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ABSTRACT

An assortment of 38 case studies illustrates efforts to integrate elderly individuals with developmental disabilities into generic aging services and into community life. The case studies include models and practice experiences that aided seniors to retire, participate in programs and services, and become part of their community's aging network. The first section describes four projects which sought to build bridges between the aging network and the disability system in New York and California. Efforts that began with "top down" or state level planning and development are then described, focusing on examples in Delaware, Kentucky, Utah, New York, and Rhode Island. Retirement assistance ventures, which pair the older person with a developmental disability with a "coach" to facilitate preparation for retirement, are discussed, with examples from England, Missouri, Mississippi, New York, and Oregon. Case studies are then offered of "pull-out" programs in New York, Connecticut, and California. These "pull-out" programs are described as programs in which two or more groups of people are drawn together for a common purpose during a distinct period of time. Senior companion ventures in Washington and New York are then described. Seven case studies describe efforts to train and otherwise aid older persons with developmental disabilities to use the services at their local senior centers, in Minnesota, Ohio, Connecticut, Wisconsin, Connecticut, New York, and Ohio. Supportive services provided in social model site programs are also addressed, with examples from New York, Kansas, and California. The final section describes adult day health model programs in Massachusetts and New York. (JDD)



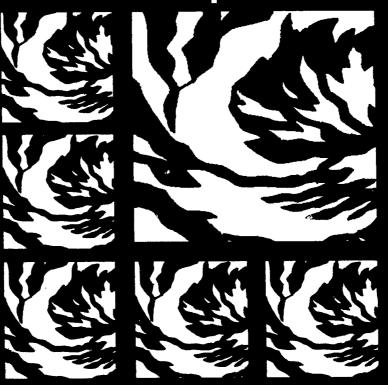
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Integration Experiences



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Integration Experiences

casebook

Program Ideas in Aging and Developmental Disabilities

Matthew P. Janicki, Ph.D. Project Director

Robert M. Keefe, M.S.S.A. Project Coordinator

1992

New York State
Office of Mental Retardation and Developmental Disabilities
Mario M. Cuomo, Governor
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Rochester School of Medicine and Dentistry, the Institute of Gerontology at Utica
College, the Brookdale Center on Aging of Hunter College,
and the Rome Developmental Disabilities Services Office.

CIPADD Team Members

Matthew P. Janicki, Ph.D. NYS OMRDD Project Director

Kathleen M. Bishop, M.S. NYS OMRDD Rome Developmental Services Office

> Sharon Bradbury, M.S. NYS OMRDD

Philip W. Davidson, Ph.D. University of Rochester

Rose Dobrof, D.S.W. Brookdale Center on Aging of Hunter College

Marilyn Howard, RN, M.S.W. Brookdale Center on Aging of Hunter College

Robert H. Keefe, M.S.S.A. Ulster County ARC Philip R. LePore, M.P.A. NYS Office for the Aging

Ronald Lucchino, Ph.D. Utica College of Syracuse University

Richard H. Machemer, Jr., Ph.D. St. John Fisher College and University of Rochester

Arthur Maginnis, M.Ed.
NYS Developmental Disabilities
Planning Council

M. Joanna Mellor, M.S. Hunter/Mt. Sinai Geriatric Education Center

Jenny C. Overeynder, M.S.W. University of Rochester

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Contributors

Marion M. Bakh

Director of Rehabilitation Services Lexington Center 465 North Perry Street P.O. Box 440 Johnstown, NY 12095

Pamela Baltes Program Manager

WACOSA 620 Sundial Drive Waite Park, MN 56387

Kathleen M. Bishop, M.S.

Assistant Director for Staff
Development and Training
Rome Developmental Disabilities
Services Office
Box 550
Rome, NY 13440

Sandra Boudreau

ARC Placer County 151 North Surrise Avenue Suite 1002 Roseville, CA 95661

Anne Benjamin, M.S.W.

Life Management Coordinator Cottonwood, Inc. 2801 West 31st Street Lawrence, KS 66046

Sharon Bradbury, M.S.P.A.

New York State Office of Mental Retardation and Developmental Disabilities 44 Holland Avenue Albany, NY 12229-0001

Maureen Brennick, A.C.S.W.

Director of Family Support Services A Very Special Place, Inc. 1429 Hylan Blvd. Staten Island, NY 10305

Theodore Bryant, M.S.W.

Community Based Support Systems Program 5127 Twenty-Fourth Avenue, S.E. Seattle, WA 98105

Alvah Canfield, Ph.D.

Director
Rose Valley Senior Citizens Center
45 Plaza Drive
Monticello, NY 12701

Ellen B. Carter, M.A.
Coordinator
SIP and GOALS Program
United Cerebral Palsy of Queens, Inc.
81-15 164th Street
Jamaica, NY 11432

Sally Cheseldine, Ph.D.

3 Ravelrig Hill Balerno

Edinburgh, Scotland EH14 7DJ

Paul D. Cotten, Ph.D.

Director
Boswell Retardation Center
P.O. Box 128
Sanatorium, MS 39112

Vicky Dickinson

Director of Program Development/ Education/Research DASH, Inc. 306 West Colton Avenue Redlands, CA 92374

Laurie-Jean Dittmann, M.A.

Director
Community and Support Services
SARAH, Inc.
33-R Water Street
Guilford, CT 06437

Diane Donaghue, R.N., B.S.N.

Director of Adult Day Care
Day at the Park
Park Ridge Health System
1555 Long Pond Road
Rochester, NY 14626

Betty Dubiel-Turgeon

Program Director
Opportunities for Older Adults
Goodwill Industries
370 Silas Deane Highway
Wethersfield, CT 06109

Herman Fogata, A.C.S.W.

Executive Director
Eastern Los Angeles Regional Center
for the Developmentally Disabled,
Inc.
3845 Selig Place
P.O. Box 31909
Los Angeles, CA 90031-0909

Teresa Galbier

Director of Developmentally Disabled Elderly Program Regional Council on Aging 79 North Clinton Avenue Rochester, NY 14604-1471 Robert Goodman, C.S.W.
JASA Outreach to Developmentally
Disabled Older Adults
3161 Brighton 6th Street
Brooklyn, NY 11235

Margaret J. Gould, M.A.

President
MARC: Community Resources, Inc.
12 Fairview Street
P.O. Box 126

Portland, CT 06480

Mary E.T. Grassi, M.Ed. Program Specialist Office for Disabled Persons Brooklyn Catholic Charities 191 Joralemon Street Brooklyn, NY 11201

Irma C. Groag, L.C.S.W.
Eastern Los Angeles Regional Center
for the Developmentally Disabled,
Inc.
3845 Selig Place

P.O. Box 31909 Los Angeles, CA 90031-0909

Julie Hammond
Program Director
Pathways Adult Dynamics
RD #2, Box 170
Corning, NY 14830

Natalie Heretz

Oneida County Association for Retarded Citizens 14 Arnold Avenue Utica, NY 13504-4759

Bruce Hughes, Ph.D.

Executive Director Pathways, Inc. RD #2, Box 170 Corning, NY 14830

Allene M. Jackson, A.C.S.W.

Program Coordinator, Aging Services St. Louis Association for Retarded Citizens 1816 Lackland Hill Parkway Suite 200 St. Louis, MO 63146

Matthew P. Janicki, Ph.D.

Director for Aging Services
New York State Office Mental
Retardation and Developmental
Disabilities
44 Holland Avenue
Albany, NY 12229-0001



Roy Lafontaine, Ph.D.
Delaware Health and Social Services
Community Mental Retardation
Programs
Rt. 1, Box 1000
McMullen Building
Georgetown, DE 19947

Carl S. Laughlin, M.S. Coordinator, Community Services Boswell Retardation Center P.O. Box 128 Sanatorium, MS 39112

Ellen M. Lewis
Director of Project Development
PEOPLE, Inc.
3909 Genesee Street
Cheektowaga, NY 14225

Ronald Lucchino, Ph.D.
Director
Institute of Gerontology
Utica College of Syracuse University
Burrstone Road
Utica, NY 13502

Susan Matthews Program Manager PEOPLE, Inc. 3909 Genesee Street Cheektowaga, NY 14225

Lucille Nahemow, Ph.D. Professor Travelers Center on Aging University of Connecticut School of Family Studies U-58 Storrs, CT 06269-2058

Gerald Nebeker, M.A. President Residential Services, Inc. 1561 N. Grandview Lane Provo, UT 84604-1019

Deborah O'Dell, M.S.W.
Program Specialist Aging &
Developmental Disabilities
Division of Services for People with
Disabilities
120 North 200 West
Suite #201
Salt Lake City, UT 84103

Jenny C. Overeynder, A.C.S.W.
Director, Training Program in Aging and Developmental Disabilities
Strong Center on Developmental
Disabilities
Box 671 - Medical Center
University of Rochester
601 Elmwood Avenue
Rochester, NY 14642

Charlotte B. Parkinson, D.S.W. Program Specialist
Office for the Aging
Brooklyn Catholic Charities
191 Joralemon Street
Brooklyn, NY 11201

Jane Rylander
Instructor and Project Coordinator
Middletown Center Adult Services
Butler County Board of Mental
Retardation and Developmental
Disabilities
1520 14th Avenue
Middletown, OH 45044

John R. Searles, M.S.
Director
Cattaraugus County Department
of Aging
1701 Lincoln Avenue
Suite 7610
Olean, NY 14750-1101

Christine Sears
Office for the Aging in Madison
County
43 East Main Street
P.O. Box 250
Morrisville, NY 13408

Nancy Sherman, L.I.C.S.W. 44 Grant Road Lynn, MA 01904

John W. Simpson, M.S.W. Boswell Retardation Center P.O. Box 128 Sanatorium, MS 39112

Marianne Smith, R.N.
Regional Administrator
Delaware Health and Social Services
Community Mental Retardation
Programs
Rt. 1, Box 1000
McMullen Building
Georgetown, DE 19947

James A. Stone, M.S.A. Project Director IHDI - Room 330 Mineral Industries Building University of Kentucky Lexington, KY 40506-0051

Lynnett F. Stucky-Mack
Director of Quality Assurance
and Specialized Services
Cottonwood, Inc.
2801 West 31st Street
Lawrence, KS 66046

Lisa M. Turner, M.S.
Director
Community Based Support Systems
Program
5127 Twenty-fourth Avenue, S.E.
Seattle, WA 98105

Sandra Vadnals
Project Director, SSNAP
Menomonie Senior Center
1412 Sixth Street
Menomonie, WI 54751

Angela Z. VanDerhoof
Executive Director
Oneida County Association for
Retarded Citizens
14 Arnold Avenue
Utica, NY 13504-4759

Patricia A. Wade, M.Ed.
Program Supervisor
Liberty Center Adult Services
Butler County Board of Mental
Retardation & Developmental
Disabilities
5645 Liberty-Fairfield Road
Hamilton, OH 45011

Kathken Hull Wickham, M.A.
OAA Coordinator
MARC: Community Resources, Inc.
12 Fairview Street
P.O. Box 126
Portland, CT 06480

Betty Zachary, CTRS
City of Portland
Bureau of Parks and Recreation
Senior Leisure Services
426 N.E. 12th Street
Portland, OR 97232

Beth Zimpel
Oncida County Association for
Retarded Citizens
14 Arnold Avenue
Utica, NY 13504-4759



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Foreword

Since the early 1970s, the fields of gerontology, geriatrics, mental retardation and developmental disabilities have increasingly sought to meet the needs of a growing number of older Americans. In 1987, new emphasis was placed on the development of such services with the reauthorization of the Older Americans Act and the Developmental Disabilities and Bill of Rights Actual access to programs and services otherwise available to the nation's elderly citizens.

These laws have fostered change to assure that all older persons, regardless of disability, have equal access to programs and services for the nation's older citizens. Part of that change has been the federal emphasis on cooperation and development which has produced an interagency agreement at the federal level, the evolution of numerous university-based training and education programs, as well as many demonstration projects. The federal initiative has challenged the states to do more in developing services for older persons with developmental disabilities and assuring their inclusion in community life.

Some states have responded to the federal example with policies that promote well-funded senior services program development. Others have just begun to respond as state developmental disabilities councils and local aging and developmental disabilities agencies have helped provide funding impetus.

The New York State Community Integration Project in Aging and Developmental Disabilities surveyed new program development and the degree of program variability throughout the United States. We solicited models and practice experiences that aided seniors to retire, participate in programs and services, and become part of their community's aging network. We wrote to administrators asking for their help in identifying individuals and projects which had been successful at integrating elderly individuals with mental retardation and other developmental disabilities into aging services or promoting their inclusion in community life.

We were pleased with the number, quality and character of case studies received in response. We chose this assortment of 38 case studies to illustrate the types of endeavors. Their diversity reflects their many variables -- some fairly common, others unique to the circumstances of each locale or situation.

These case studies were written by practitioners, administrators and other program personnel from around the country and abroad who have worked at integrating elderly individuals with developmental disabilities into generic aging services. They were written to reflect and share each authors' experiences -- both positive and negative. Some authors provided elaborations, some did not. With each study, we worked with the authors to provide a background of the project as well as some final thoughts. We edited for consistency, terminology and length, but the ideas and descriptions are those of the authors.

We offer our thanks to all who submitted case studies and in particular to those who stayed with us during the editing and acceptance process. Their time and willingness to share has made this *Casebook* a more valuable tool for consumers, families, administrators, and practitioners who are concerned with older persons with mental retardation and other developmental disabilities.



In many communities, the first step to providing access to typical senior services for older persons with a developmental disability has been building a bridge between the aging network and the disability system. Such bridging is done for several reasons. One reason is a need for the coordination of referrals, services (such as transportation), site sharing, and dealing with the whole range of day-to-day problems that older persons experience. Another reason is the need to ensure that monies that underwrite the programs for older persons with developmental disabilities flow quickly and properly to the providers within the aging network. Other reasons include means to effect greater acceptance of seniors with disabilities among the public and age peers and encourage fuller inclusion of seniors with a disability within mainstream aging network programs.

The process of bridging networks can take many forms. We came across many excellent examples. The ones contained in this section represent the types of efforts that have been undertaken on a system-wide basis and on a local level. The key features of these efforts are that the participants agreed to cooperate, agreed to achieve common ends, and agreed to shape public policy that supported bridging. Such efforts, however, were not without their difficulties. Bridging efforts, as we have found, can be affected adversely by a number of factors, including changes in key personnel, money problems, shifts in priorities of participating agencies, and frustrations over the lack of agreement of group objectives or timeframes.

Although the four case studies in this first section illustrate differing approaches to bridging, they all echo a similar theme. Each project began as a modest public policy effort and then progressed to greater ends. Some began with a formal charge, others evolved from informal processes. Interestingly, the most productive projects were those that involved the broadest number of participants and which had the continual backing of state or regional administrative agencies

We have also observed that network bridging endeavors often start with modest ventures, bringing together strangers who, over time, formed collegial bonds that strive for the community good. Many of these efforts led to or were associated with outcomes that produced interagency agreements or other forms of formal social bonding. Some of the projects needed outside stimuli to begin their formative activities; others did not and evolved naturally.

The lessons learned? Interagency efforts can produce constructive ends and lead to benefits that bridge the aging and disabilities systems. Sometimes they need formal mechanisms to succeed, other times the social bonding that occurs has greater value than formal structures. In all instances, the successful efforts become partnerships with each network/system equally involved and benefitting.

Section 1: Bridging Networks



Council on Aging & Developmental Disabilities of Greater New York

Charlotte B. Parkinson¹

Case Abstract: This case study describes the experiences of a group in New York, New York in setting up an interagency council on aging and developmental disabilities. The process began under the tutelage of a university-based center on aging, but then evolved into a multi-agency effort. The council published a consumer brochure and a glossary designed to help bridge the two networks; sponsored a lecture series and collected data that were used to help agencies in developing senior programs. This example shows that such efforts can produce results within the most complex social environments.

Introduction

In the United States today there is a relatively new and rapidly growing population of persons who are both elderly and developmentally disabled. Although there is disagreement about the size of the group, there is consensus that along with the general population -- which is experiencing considerable increase in life expectancy -- this group is experiencing an increase in life expectancy. This increase in longevity is a result of the advances in health care and improved standards of living which have taken place over the course of recent decades.

The 1987-1990 Plan for Services, issued by the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD), estimated that the prevalence of older New Yorkers with a developmental disability between age 45 and 64 was 25,700 and age 65 and older was 15,900. Prevalence estimates for New York City were for 10,100 adults with a developmental disability between the ages of 45 and 64 years and 6,700 adults 65 and over.

These numbers represent a population with unique and special needs due to the junction of aging and lifelong developmental disabilities. It is important to remember, however, that these numbers represent people, people who happen to be aging and who happen to have a handicap.

Because relatively few persons with a devel-

opmental disability survived into old age, there were very few, if any, services for them. However, their needs are now being addressed by a variety of programs in New York City and New York State as well as in other areas of the United States. In order to address the needs of this population, a coordinated and collaborative approach to services from both the aging and the developmental disability resource systems is required.

The history of the work in New York State to develop linkages and foster contact between the fields of aging and developmental disabilities is important because it led to the creation of 13 separate aging and developmental disability network groups, of which the New York Council is the largest.

In 1983, the OMRDD issued a report on elderly persons with a developmental disability. The report led to a state conference on this population which was held in 1985. Also in 1985, the Developmental Disabilities Planning Council (DDPC, a planning, funding and coordination agency which receives federal dollars from the federal Administration on Developmental Disabilities for innovative projects) chose the aging of adults with developmental disabilities as an important area that needed to be addressed. The New York State Office for the Aging (SOFA) and the OMRDD began to explore options for future program development for elderly individuals with developmental dis-



Correspondence should be addressed to Charlotte B. Parkinson, D.S.W., Program Specialist, Office for the Aging, Brooklyn Catholic Charities, 191 Joralemon Street, Brooklyn, NY 11201. An earlier version of this case study was presented at the annual meetings of the American Association of Mental Retardation in Washington, D.C. and Chicago, Illinois and at the Region VI AAMR Conference in Toronto, Ontario, Canada. Dr. Parkinson served as one of the first cochairs of the Council.

abilities which, in 1986, led to the Developmental Disabilities Project. The purpose of the project was to test the feasibility of serving persons with developmental disabilities in aging network congregate settings.

Five years ago in New York City, workers in the fields of aging and developmental disabilities began to realize that there was a need in the city for information exchange and cooperation and contact between professionals in the two fields. Recognition of this need led to efforts which brought people from the aging and developmental disabilities fields together on a regular basis and to the formation of the Council on Aging & Developmental Disabilities of Greater New York — formerly known as the New York City Task Force on Aging and Developmental Disabilities.

The Council on Aging & Developmental Disabilities of Greater New York consists of over 50 policy and planning developers, program directors, service providers and other concerned individuals from both developmental disability and aging agencies in both the public and private sectors. Council members meet on a monthly basis to share information about elderly persons with developmental disabilities, to produce and develop linkages between the aging and mental retardation/developmental disabilities systems, and to plan services which will improve the quality of life for elderly persons with developmental disabilities. The Council collaborates with other organizations to advocate for the rights of the elderly and persons with disabilities, sponsors lecture series, publishes informational material, conducts needs assessment, and performs research projects. The Council has been instrumental in identifying areas for government to fund demonstration projects. In 1989, for example, a Council survey identified community integration and housing as critical areas for service development. As a result, one housing demonstration and five integration projects were funded in New York City.

This case study describes how the Council emerged, its current activities, future plans and

its work on behalf of elderly New Yorkers with developmental disabilities.

Project Description

Several events occurred in 1987 in New York City which led to the formation of the Council on Aging & Developmental Disabilities of Greater New York. First, New York City's Brookdale Center on Aging of Hunter College - an educational center for training and research in aging issues -- completed a two-pronged study which explored the situations of elderly parents who had offspring with mental retardation and investigated the extent to which aging agencies had experience with elderly parents.

The striking conclusion which emerged from this study was the need for contact and cooperation between the fields of aging and mental retardation/developmental disabilities. At the same time, the OMRDD and the Brookdale Center implemented their long-standing interest in putting together a plan for bridging the two systems. The Brookdale Center and the OMRDD, together with the Mental Retardation Institute of Valhalla and the Hunter/Mt. Sinai Geriatric Education Center, convened a planning committee to help design a conference which would get the two networks together to start sharing ideas. The conference took place in September 1987, and was seen as an initial effort to educate and sensitize the participants to each other. Nearly 150 people from the social service and health professions in the aging and developmental disabilities networks attended. The conference consisted of speakers from both fields and workshops which dealt with issues such as older caregivers, residential programs, day care and physical signs of aging.

As a result of the conference, participants expressed interest in setting up a forum for continued dialogue between the aging and developmental disabilities networks. They expected that increased information exchanges, advocacy activities and combining the two networks' services would result from the forum.



This planning group formed the nucleus of the Task Force on Aging and Developmental Disabilities and held its first meeting in January 1988. The goal of the Task Force was to develop a document that could be used by professionals in the fields of aging and developmental disabilities to plan future programs and services for elderly individuals with mental retardation and developmental disabilities in New York City.

The Task Force established itself and was recognized and supported by the New York City Department for the Aging, OMRDD and the Council of Senior Centers and Services of New York City Later, the Task Force applied for and received a grant from the state's developmental disabilities council to plan for the needs of elderly persons with mental retardation who resided in New York City.

A major objective of the grant was to conduct a research study. Initially, the members of the Task Force formed two committees: one dealt with salient issues which affected older persons with mental retardation and another in which their demographics were studied. The Task Force then heard and discussed the committees' findings.

In addition, the Task Force oversaw the hiring of two research assistants and elected two co-chairpersons: one of whom had expertise in disabilities and the other expertise in aging.

The two co-chairs appointed and served on a research committee. This committee provided a definitive statement of the purpose of the research, clarified the role of the Task Force members, and worked on the strategy and methodology of the study design. The committee also oversaw the construction of a survey instrument, gained support for the survey by enlisting the help of the Inter-Agency Council of Developmental Disabilities agencies in New York City and administered the survey.

The purpose of the survey was to gather demographic and service information in order to assess the size and need of the population of older individuals with mental retardation and other developmental disabilities who reside in New York City.

Over the course of the fall of 1988, we formed a Conference Committee that planned a conference held in December 1988 in conjunction with the Hunter/Mt. Sinai Geriatric Education Center. The conference offered in-service training and education to staff who work with elderly individuals with mental retardation.

In February 1989, another committee was formed to develop program guidelines for day programs for seniors that would conform to Medicaid guidelines.

The Task Force met monthly. The meetings provided not only a forum for discussion, but also for education. Initially, at each meeting, two or three people in the field described their programs. For example, a social worker from a Staten Island agency presented her outreach efforts to elderly parents of children with mental retardation.

As the Task Force evolved, the scope of the presentations was broadened to include advocacy and fiscal issues. There was always a lot of discussion around the presentations, especially around how to improve linkages between the two systems. More recently, vigorous discussions on policy and ethical issues were held during which people in the field gained new ideas from our presentations. The Task Force's efforts served to improve linkages and collaboration among public and private agencies in both networks.

After several years, the Task Force members decided to make the organization more formal. Thus, the Council on Aging & Developmental Disabilities of Greater New York was created. The council developed a formal operating framework, adopted by-laws, held annual elections, and sought to secure operating funds.

The council has also broadened the scope of its activities to include the following:

Publications: The Council developed and published a Consumer Brochure to inform consumers of available services of both systems in the five



boroughs of New York City. The Council also developed and published a Glossary of Terms, Concepts and Resources in the Fields of Aging and Developmental Disabilities. The purpose of the Glossary was to improve technical communication between the aging and developmental disabilities systems. (The consumer brochure and glossary are available upon request from the author). We hope to update the Brochure and to publish a newsletter and some monographs, for example, on topics such as vision loss and hearing difficulties in elderly persons with a developmental disability.

- Advocacy Activities: The Council increased its advocacy activities. For example, at one of the meetings, council members broke into four groups and worked on four issues which the Council felt should be emphasized on the reauthorization of the Older Americans Act. Each group came up with written comments and suggestions which were later developed into a letter by the Executive Committee and sent to the appropriate persons in Washington, D.C. Concerns relative to premature aging, adult day services, planning, and housing were raised.
- Lecture Series: During 1989-1990, the council developed and sponsored a lecture series. Six lectures on topics such as creative programming, adapting the environment, and sexuality were held. The series was so popular, during 1990-1991, we offered a second series. Topics included bereavement counseling, art and dance therapies, and retirement activities. In July 1991, the Continuing Education Committee met to plan the third lecture series which included new issues in aging and research issues on aging/developmental disabilities.
- Research: The Council finished the second part of its original study. The study investigated the size and potential growth of the population of elderly persons with developmental disabilities in New York City and also examined the extent to which aging agencies are involved with such individuals.
- Coordinating Work Committees: The Council was instrumental in identifying areas in which government could fund demonstration projects.

The Council received support during its early phases by a grant from the state developmental disabilities council. The monies were administered by the Brookdale Center on Aging and used to support Council activities, including clerical and "dministrative costs. Thanks to the efforts of the council liaison from the Brookdale Center, we were able to secure additional monies from the One-To-One Foundation (which funds projects in developmental disabilities).

The following committee structures were established by the Council:

- An executive committee consisting of the two co-chairs, former co-chairs, the executive director of the Hunter Mount Sinai Geriatric Center (which is co-sponsored by and located in the Brookdale Center), representatives from the New York City Department for the Aging, the New York City Bureau of Mental Retardation and Developmental Disabilities, and the chairs of the Council of Education and Training and Publication committees, the City University of New York (CUNY) liaison, and other members-at-large. The purpose of the executive committee is to provide leadership to the council.
- An education and training committee consisting of the chair, the council co-chairs, and representatives from the aging and developmental disabilities fields. The purpose of this committee is to plan and implement educational events such as the lecture series, in-service training and conferences, and to alert people in aging and developmental disabilities to events in each others' service systems.
- A communications committee consisting of the chair, the council co-chairs, and the chairs of specific projects, for example, the Glossary or Consumer Brochure. The purpose of the Communications Committee is to oversee the production and publication of resource materials and public relations for the council.

The Brookdale liaison and the staff person of



the council sit ex-officio on all committees.

Lessons Learned

The lessons learned by carrying out this project can be grouped into four categories: funding, "key people," a meeting place, and leadership.

Funding is the crucial element for a viable taskforce/council.

Monies are needed for basic components such as minutes, agenda, and meeting notices. An administrative person to take charge of the above is essential, as is secretarial and clerical help to back up the administrator. Funding is needed to cover the cost of publications and conferences.

Developmental disabilities council monies are "seed" monies which prevent it from being a source of permanent funds. The fiscal situation in many states is so tight that no state or city government agency can start a new funding initiative. City-wide councils might be able to be added to a larger federal initiative, perhaps as a demonstration project model. Another way of obtaining funds is through member dues, charging for the lectures rather than just asking for a contribution, and increasing the in-kind help of photocopying and mailing from member agencies. Establishing a fund raising committee can help as a first step.

Grant money should be administered by the organization that releases staff members for administrative and clerical work. Brookdale Center is an educational and training center which is automatically connected to a larger system. The Council has the opportunity for informal and spontaneous communication, and access to a variety of people in various professional disciplines and to new developments in their fields. The fact that Brookdale is located at a Hunter College site enables the Council to use a large classroom for the lecture series and conferences and the cafeteria for lunches.

State and local support is crucial.

Our council has been very fortunate to have

three persons at the state level who are accessible to us. They come to local meetings, work on committees, such as the Committee for the Conference in 1988, and are always available for consultation.

A supportive meeting place is essential.

The space must be accessible, conveniently located, and consistently available. The Council was fortunate to have use of the conference room at The Lighthouse (a major New York City agency serving persons who are blind) for the first year and subsequently the conference room at the offices of the United Cerebral Palsy Association.

Involved and committed leadership is important.

The co-chairs must be able to convene a large group of diverse individuals with different levels of expertise and abilities and to motivate them to move forward to accomplish the Council's goals. The co-chairs should bring their expertise from the aging or disability networks.

There also has to be a system to select the co-chair candidates. Serving on a committee demonstrates interest and motivation, and chairing a committee can be a step towards assuming the responsibility of co-chair. The committees provide structure and stability, and are vehicles to accomplishing tasks, such as putting on a conference or developing a publication.

Parting Comments

Our council is vibrant and effective because it operates on both a formal and informal level. It receives funding and support from the formal system of government agencies at the state and local level, and from private agencies. Within this framework, council members are able to exercise their individual talents to effect linkage, collaboration and education. For example, our council has been very active in bringing together people from the aging and developmental disabilities networks to meet each other and get to know each other's concerns. Specifically, when we were developing our lecture series we decid-



ed to hold the lectures in the mornings, followed by a lunch, and scheduled these lectures on the same day as the afternoon council meetings. We found that the lunches brought policy and planning people together with program directors and providers. The lunches also gave these professionals a chance to meet new people in a relaxed way, and made them feel comfortable enough to pick up the telephone and contact one another later as needed.

We feel that contact between the two networks has been extremely beneficial. For example, people in aging have learned that elderly persons with a developmental disability are a heterogeneous group. They have different health situations, cognitive abilities, and family constellations. People in the developmental dis-

abilities system have learned about some of the critical issues in aging, such as retirement and isolation. They know now that although some of the aged are living well, there are large numbers who are ill, frail and homebound. As the council moves forward, we learn more from each other, discussing issues, listening to the presentations, and involving ourselves with the work of the committees.

The council has made a significant contribution towards improving the lives of elderly New Yorkers who have had a lifelong developmental disability by increasing the public's general awareness of them and their needs. In addition, the council has carried out education and training of professionals, advocacy activities, planning services and program development.

Los Angeles Area Regional Cooperation Project

Herman Fogata and Irma C. Groag¹

Case Abstract: This case study describes the experience of a regional center in the East Los Angeles, California area in networking and opening up aging network services to older persons with a developmental disability. Using development funds from a federal grant, this project set about organizing and networking the developmental disabilities and aging networks to enable a greater number of seniors with developmental disabilities to use aging network programs and activities. The project found that through creating systems changes at various administrative levels, elderly individuals with developmental disabilities were able to be integrated into generic services. The cooperation project was able to bring together agencies from both networks, including the state, into a unified body to plan, cooperate and expand service options.

Introduction

The Eastern Los Angeles Demonstration Project for Aging Persons with Developmental Disabilities was initiated because we felt that older persons with developmental disabilities were not receiving the benefits of programs/services that were being provided to their same age peers who did not have a developmental disability. We observed that seniors with developmental disabilities were being served exclusively in segregated programs which gave little attention to their special needs and that the major systems for delivery of ser-



Correspondence should be addressed to Herman Fogata, ACSW, Executive Director, Eastern Los Angeles Regional Center for the Developmentally Disabled, Inc., 3845 Selig Place, P.O. Box 31909, Los Angeles, CA 90031-0909.

vices to the elderly were exclusive of each other -- aging persons without a developmental disability were being served in one system and aging persons with a developmental disability were being served in another system. These dual systems reinforced the lack of integration among services that focused on the aged.

Given this situation, the Eastern Los Angeles Regional Center for the Developmentally Disabled applied for and received a grant from the Administration on Developmental Disabilities to:

- Establish a specialized service system for persons who were aged and who also had developmental disabilities.
- Seek the cooperation of systems serving the non-handicapped aged in "sharing" resources.
- Create a specialized administrative unit within the regional center to act as a focal point for all activities related to serving the aged persons with developmental disabilities.
- Integrate aged persons with a developmental disabilities into systems which traditionally did not serve them.
- Channel existing financial resources currently provided to non-handicapped aged persons to aged persons with developmental disabilities.

Project Description

The "target" population identified for this project included persons who were fifty years of age or older and who had a developmental disability. At the beginning of the project there were 115 older persons in this age category in the Eastern Los Angeles Regional Center System. Of this group, 39 lived in their own home, 36 resided in state hospitals, 5 resided in skilled nursing facilities and 28 lived in community care facilities.

Our project focused on 75 persons: those living at home (39) and those living in commu-

nity care facilities (36). Ten persons were of normal intelligence, 26 had mild retardation, 23 had severe mental retardation and 32 had profound mental retardation.

Services to this population required the involvement and participation of a variety of agencies. Even though the regional center was responsible for case management, a number of other public and private resources were tapped to provide a range of programs and services, including a social day program (operating five days per week), an adult educational services program (operating six hours per day provided through the Los Angeles Unified School District), an art component providing opportunities for creative expression and supported by the Los Angeles Unified School District; recreational services provided through The Performing Arts, Division of Cultural Affairs, City of Los Angeles: The Grand Peoples Company (a privately and publicly funded tour service); and nutritional services in the form of congregate meals provided through the resources of Title III of the Older Californians Act to the Los Angeles Unified School District.

In addition, we were able to secure transportation services through the developmental services system as well as generic services, funded through Proposition A and the Older Californians Act and contracted by the Los Angeles City and County Area Agencies on Aging. Health care was obtained through funds authorized under the Older Californians Act and contracted through the Los Angeles County Area Agency on Aging. Mental health services were accessed through ALMA Family Services under a contract from the Los Angeles County Mental Health Department. The service provides counseling to persons who have a dual diagnosis of a developmental disability and a mental illness.

Living arrangements focused on age-related needs as well as served as the link between the senior with a developmental disability and his/her community resources. Other support services were drawn from the resources of the Los Angeles County Department of Public Social Services and intended for homemaker



chore services. Bet Tzedek (a privately and publicly funded legal service specifically designed for aged persons), provided legal assistance. Lastly, employment services (in which seniors who do not have a handicap are hired under Title V of the Older Californians Act) were targeted for peer assistants. A number of seniors are trained and provided with the opportunity for continued employment within the developmental disabilities system as homemaker/chore or respite workers.

Because of the strategic position held by the area agencies on aging in both the city and county of Los Angeles, and the resources which these agencies controlled, they were particularly important in the implementation of this project. Their influence and leadership were helpful in channeling resources which were available to the elderly in general. Also, in the later stages of the project, the State Department of Developmental Services and the California Department of Aging played a "key role" in coordinating services through the use of a memorandum of understanding (MoU) between the two departments and their local agencies.

The project was carried out in East Los Angeles. East Los Angeles is a predominately Hispanic, low income community.

In the planning and implementation of this project, we undertook the following generally accepted guidelines:

- Define the population.
- Assess the population's needs and the resources needed to meet its needs.
- Define the service system and identify the gaps in the system.
- Determine how best to address the service gaps.

Our task, therefore, was to work towards enabling seniors with developmental disabilities to access and use the generic aging network services available to other seniors in the East Los Angeles area. What follows is a broad overview of some of the processes and problems we encountered while accomplishing this goal.

The natural tendency to resist changing the system required action at a higher level of administration than working only at the local neighborhood level. The process of change was accelerated when the State Department of Developmental Services and the California Department of Aging agreed to establish a pilot project involving two area agencies on aging and two regional centers for the purpose of developing a method of coordination. This pilot project resulted in developing a plan of coordination which was finalized into a memorandum of understanding between two systems.

The concern over expanding resources to a "new" group, that had not been receiving attention from generic agencies, slowed the process of getting services to the older person with developmental disabilities. Because persons with developmental disabilities make up a small percentage of the general aged population, it is only natural that priority attention would not be given to this group. Strong advocacy efforts had to be made and reliance on the agreements as set forth in the State MoU had to be articulated.

In general, it was recognized that there was a need, but the reality of limited resources for the general population worked against sharing more resources. In addition, apprehension towards a population that was not understood became an obstacle to integration. Because the generic agencies which operated senior citizen centers had not been exposed to persons with developmental disabilities, there was concern over their effect on ongoing programs. We also found that since senior citizen centers for the general population geared their programs to a population with somewhat different needs and life styles, it was difficult to integrate the seniors we had in mind into their on-going programs.

The current system for serving persons with developmental disabilities -- aged or otherwise -- is based on a "full day" of programming. Community care facilities and parents have



come to rely on the persons being away from home for at least six hours per day. In the initiation of the project and during the course of its implementation, several problems arose which required attention and assertive action by the regional center. The major problems were the:

- Lack of awareness of the existence of aged older persons with developmental disabilities; and generic agencies which were unaware that this population existed.
- Concern over the need to share limited resources with "another" group of elderly citizens who had not been considered as having a right to the on-going services.
- Lack of interest on the part of generic agencies serving the aged to change "the system" in order to accommodate a special group that represented only a small segment of the aged population.
- Fear and apprehension of generic service providers to integrate the seniors with developmental disabilities into on-going programs.
- Conflict between the needs of aged persons who did not have handicaps who were scheduled to engage in brief self-selected activities and the needs of older adults with developmental disabilities who needed more extensive programming.

Improving the awareness among aging network agencies of older persons with a developmental disability required an assertive role on the part of the regional center. Many frequent contacts had to be made with generic agencies in order to educate these agencies on the existence of this special group as well as about their needs.

Audio-visual materials were used to acquaint the generic agencies with the issues which confronted persons with developmental disabilities. Site visits to agencies and presentations at a meeting of the California Commission on Aging by staff and by an older person with a developmental disability helped to breakdown the ste-

reotype that this population is "different".

Access to the planning and resource allocation process of generic agencies, such as the local area agencies on aging (AAAs), was achieved when the project coordinator joined the AAAs Advisory Committee and eventually was elected an officer to this Advisory Committee. Becoming an active member was beneficial.

Every meeting provided an opportunity to confront personnel from generic agencies with information on seniors with developmental disabilities. On several occasions, committee meetings were held at the regional center which gave generic agencies a chance to know more about people with developmental disabilities.

As the project progressed, inter-agency contacts expanded from meeting with the directors of local neighborhood generic services to meeting with higher administrative level personnel. Meetings were held between the City and County program administrators and the regional center director. These meetings helped to bring others to work together at the neighborhood level.

An advisory committee was established to obtain support for the project and assure that the responsible agencies would coordinate their services with our project. This committee was composed of representatives from the following fields of service: health prevention and health maintenance, physical therapy and occupational therapy, nutrition, transportation, social recreation, mental health, employment, housing and education.

However, initially the committee failed to materialize as a vehicle for group decisions and planning. What resulted was a process of one-on-one planning and receiving commitments. The lack of group cohesion resulted primarily because each agency believed that those persons with developmental disabilities represented only a small percentage of the general caseload. Therefore, the urgency or necessity of meeting regularly was not seen as important.



One of the benefits of the project was the development of interagency agreements. The MoUs were products of joint meetings between the city and county area agencies on aging and the regional center. The barriers to better coordination were acknowledged and agreements regarding how to deal with them were reached, which became the substance of the MoUs. There was also a MoU between the State Departments of Developmental Services and Aging. This MoU committing the two departments to working together was important for communicating an attitude of cooperation which was expected to permeate throughout the local level. Certainly the MoUs helped impress the need for the coordination of efforts. The project coordinator had to be very active in advocating for aged persons with developmental disabilities, and numerous one-on-one advocacy activities were carried out to overcome system problems.

One additional facet of our project was centralizing caseloads. Prior to the project, all older clients were carried by a number of different case managers. Centralizing all seniors with one case manager created a specialist with interest and experience which had been lacking.

Since this project was initially undertaken, we have had the good fortune to organize a Los Angeles area coordinating group on aging and developmental disabilities.

Lessons Learned

A number of benefits for the delivery of services to aged individuals with developmental disabilities come from bridging projects.

Due to specific efforts, there was a greater awareness among generic agencies that served the general aged population, of the existence of this sub-population in our community. This greater awareness, combined with an assertive effort on behalf of the persons with a developmental disability, caused a flow of resources to this group that did not exist prior to our project. The integration of the individuals with developmental disabilities into generic senior citizen programs began to take place. Although a number of problems ex-

isted in terms of more extensive use of regular programs, a breakthrough had been made. Individuals who previously had not been able to participate alongside age peers in specific program activities are now utilizing the facilities of senior centers.

The state's interest in integrating people with developmental disabilities with other seniors can be expanded to highlight this issue.

State policy on integration received a big boost as the success of the project proposal led to MoUs between seven regional centers in Los Angeles and the city and county area agencies on aging. There is now an ongoing, established relationship backed by state level support from the State Department of Developmental Services and the Department of Aging. Other regional centers throughout the State have also developed working MoUs with local area agencies on aging. The separatism which existed between two systems -the regional centers and the area agencies on aging -- has diminished and a local committee composed of representatives of both systems has been established.

Full integration (i.e., aged persons with a developmental disability on an individual basis participating alongside other aged individuals) can not always take place.

The level of impairment of some persons will continue to be a barrier and require that they receive separate program activities.

It is difficult to stimulate interest on the part of some generic agencies to serve the aging person with a developmental disability.

This group represents a very small percentage of the general aging population being served and their number does not command much attention. The problem of numbers also effects the regional center system and the State Department of Developmental Services. With the pressure of large caseloads of individuals who are not aged but have a developmental disability, the priority in staffing has been given to attending to the non-aged first. The Department of Developmental Services has not recognized the importance of granting

regional centers additional staff that specialize in working with this group.

Parting Comments

The integration of aging persons with developmental disabilities into generic services which serve the general aged population is a slow and time consuming process. Stereotyped ideas and attitudes about people with developmental disabilities need to be overcome.

Generic agencies that currently control resources for the general aged population are reluctant to "share" their resources at a time when resources are becoming more and more scarce. One can not rely solely on "friendly

persuasion" to open doors to seniors with developmental disabilities which is why the MoUs at the state and local level are so important.

Agencies undertaking the task of serving this special population of aging persons should be prepared to commit the necessary staff time required for assertive advocacy. However, the efforts to meet the needs of this special population has many beneficial by-products. The general service systems and organizations that are active in the field of aging have become much more aware of this group, and in many cases are willing to respond to their needs. Movement towards better integration of the various systems that normally serve this population -- but which are isolated from each other -- has started, and promises to create a better way of serving this special population in the future.

Monroe Council on Aging and Developmental Disabilities

Jenny C. Overeynder¹

Case Abstract: This case study describes the experience of a county-based consensual planning and coordination process, set up through a university, that was used to bring together representatives from the aging and developmental disabilities networks in Rochester, New York. The project resulted in the formation of a council that served as a forum for information sharing, networking, data collection; sponsoring training events, conferences; and consultation on integration activities. The Council discovered that professionals from these two fields are able to work together in a productive way to bring about positive changes in programs for older individuals with developmental disabilities.

Introduction

The Monroe Council on Aging and Developmental Disabilities was established in 1987 as an outcome of a comprehensive, communitywide planning effort focused on services for older persons with developmental disabilities.

Monroe County is a predominantly urban county in upstate New York. It encompasses the city of Rochester and several rural communities. There are several major industries, such as Eastman Kodak, Xerox, Bausch and Lomb, five hospitals, as well as a number of educational institutions, including the University of Rochester. It has a well educated workforce and a large service network.



Correspondence should be addressed to Jenny C. Overeynder, ACSW, University Affiliated Program in Aging and Developmental Disabilities, Strong Center on Developmental Disabilities, Box 671, University of Rochester Medical Center, 601 Elmwood Avenue, Rochester, NY 14642.

The Monroe Council is a voluntary organization which consists of representatives from the aging and developmental disabilities networks. All members of the council have a direct involvement with older persons with developmental disabilities. The group meets on a regular basis and is primarily a vehicle for networking, sharing and disseminating information.

Council members consist of representatives of the Finger Lakes Health Systems Agency, the Regional Office of the New York State Health Department, the Monroe County Office for the Aging, the Monroe County Department of Social Services, the Monroe County Department of Mental Health, the Monroe Developmental Disabilities Services Office, the Regional Council on Aging, the Advocacy Center for the Developmentally Disabled, the Association for Retarded Citizens, Lifetime Assistance, Inc. Montgomery Neighborhood Association, Visiting Nurse Service, Rochester Area Association of Homes and Services for the Aged, Park Ridge Hospital, Monroe Community Hospital and the University of Rochester. In addition, it has representation from family members of persons with developmental disabilities.

Project Description

In Monroe County, as well as in other parts of the state and throughout the country, people have been aware that much needs to be done to promote the coordination of services for older persons with developmental disabilities. New York State has a history of making linkages between the service providers who work with the elderly and those who work with persons with developmental disabilities. About five years ago, the two networks began collaborating together in Monroe County.

In 1986, the University Affiliated Program for Developmental Disabilities (UAPDD) and the Center on Aging of the University or Rochester received a supplemental grant from the Administration on Developmental Disabilities. The funds from the grant were to be used to organize a consensus planning conference. The goal of the conference was to create a taskforce

which consisted of community representatives from governmental and voluntary agencies, educational institutions and advocacy groups from the service delivery system which were geared toward aging persons and persons with developmental disabilities.

The first step was to identify all the parties in Monroe County who needed to be brought together to form such a taskforce and to agree on a process to do so. A small steering committee was formed to help the UAPDD and the Center on Aging with this task. It consisted of the directors of the Monroe County Association of Retarded Citizens, the Monroe Developmental Disabilities Services Office, the Monroe County Department of Mental Health, the Monroe County Office for the Aging and the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD). The group invited some others to join them, and much thought was given to the organization of the planning conference.

The intent of our effort was to bring together decision makers from both networks and to explore the potential for network building, to assess existing needs and resources, to identify obstacles for service delivery and to determine which services and resources could or should be developed. Funding support for the conference was provided by local voluntary organizations as well as by the state developmental disabilities planning council. Having some funds available meant that the registration fee could be kept very low. A mailing list of over 400 individuals was compiled and formal invitations were mailed.

The steering committee decided to use a consensus planning format and engaged a facilitator who was experienced with this model and who had facilitated similar conferences in the state on different topics with good results. The method used was one of problem identification, consensus building and agreeing on strategies to affect positive change towards these problems.

Over 100 persons agreed to participate in the taskforce and attended the planning conference which was held in early 1987. They met for



three and a half days. Using a consensus planning model, they spent the entire time in small groups, brainstorming about the problems, coming up with possible solutions for these problems, and negotiating in a group format which strategies might be most effective to tackle the various issues. The taskforce generated a plan which sought to:

- improve the coordination or care, collection of data, provision of training; and
- address regulatory and legislative issues for the population of older persons with developmental disabilities.

The result of this plan was the formation of the Monroe Council on Aging and Developmental Disabilities which would continue as a network that could discuss the plan in detail and implement its recommendations. The Council formally began in the summer of 1987. The group has met on a regular basis since that time and has engaged in a series of activities focusing on services for older persons with developmental disabilities.

The Council was made up of representatives of a number of constituencies which included the Finger Lakes Health Systems Agency, the Regional Office of the New York State Health Department, the County Office for the Aging, the County Department of Social Services, the County Department of Mental Health, the Monroe Developmental Disabilities Services Office. the Regional Council on Aging, the Advocacy for the Developmentally Disabled, consumers and family members, voluntary agencies providing services to persons with developmental disabilities, senior centers, the academic community, the United Way, nursing homes, agencies providing services to minorities, and home health care agencies.

Although the initial thought was to immediately establish a series of committees, the group first wanted to collect data and then decide on which direction to go. The decision was made to meet monthly and to take some time at each meeting for the members to explain their individual programs. This opportunity gave the

group a chance to understand each other's client populations, needs, problems, opportunities for service, as well as gain an understanding of the rules and regulations governing each program.

At the same time some members from the taskforce assisted the UAPDD and the Center on Aging (the original conveners of the taskforce) to form an academic consortium that took a look at the need and opportunities for training service providers as well as the academic community on issues pertaining to aging and developmental disabilities. This academic consortium grew to a membership of 40 persons, representing 10 institutions of higher learning in the Greater Rochester area, and also included service providers and governmental agencies. The academic consortium met separately from the council, and progress reports were made at each council meeting.

In the fall of 1987, the council and the Academic Consortium engaged in two activities. First, a needs assessment was undertaken to survey training needs in the community. Second, a community survey was made to collect information on the number of persons served who were aging and had a developmental disability.

The training needs assessment formed the basis of a successful grant application to the Administration on Developmental Disabilities which was awarded to the UAPDD and the Center on Aging at the University of Rochester in 1988. Extensive plans were made to institute a regional training program, which provided both inservice and preservice training in the western part of New York State. The fact that the plan was supported by a large number of educational institutions -- all of whom enthusiastically supported the idea of incorporating material on aging and developmental disabilities into their course offerings -- was an important factor in the fact that the grant was awarded.

The data collection was done by surveying all the agencies that had participated in the taskforce. It was very difficult to get an exact estimate of the numbers of older persons with developmental disabilities in the community.



National estimates have found that fcr every person known to the developmental disabilities services system, there are three persons in the community who have never received any services and therefore do not turn up on any official count.

In New York State, the OMRDD maintains a central registry for all persons with developmental disabilities who are being served through its system. Because one of the council members represented the state's Developmental Disabilities Services Office (DDSO), she was able to obtain the data for Monroe County. The Finger Lakes Health Systems Agency and the Regional Office of the New York State Health Department surveyed all the nursing homes in the area. The rest of the agencies were surveyed by questionnaire. Not surprisingly, when the results were tabulated, we found that there was a substantial number of persons identified who were not known or had never been served by the developmental disabilities system.

The data showed us that in 1988, there were in Monroe County a total of 341 older persons with developmental disabilities, of these 227 were in the DDSO database.

Several other developments occurred in Monroe County in 1987 and 1988. One of the founding members of the council, the Regional Council on Aging -- a large voluntary provider for services to the elderly in Rochester -- received a demonstration grant from the state developmental disabilities planning council to assist with the integration of older persons with developmental disabilities into generic aging services.

At the same time, the state's DDSO opened a new community residence specifically constructed to house older persons with developmental disabilities. Plans also were under way to provide day programming at an adult day health program that was to be operated by one of the large hospitals in the community.

During that time, several service providers became increasingly aware of the need to include aging persons with developmental disabilities among their clientele. A number of senior centers and adult day programs made a concentrated effort to provide programming for this group.

In 1989 and 1990, the training program in aging and developmental disabilities at the University of Rochester got off the ground and the council participated in the design and delivery of a series of inservice programs. These programs started with a lecture series, and grew into a large number of workshops and courses offered throughout the western part of the state. Particularly successful was a major conference in Rochester, in the winter of 1990, which focused on the comparison of the two service systems: aging and developmental disabilities, with input from state and local officials, as well as comparisons between the residential and the day services that are being provided for both populations. Council members helped with the planning, gave valued input into the program and shared their mailing lists. As a result, 300 persons attended the conference.

"Typically, people who work in the field of aging know each other quite well, as do people who work in the field of developmental disabilities. However, as in other communities in the country, representatives from these two systems did not know much about each other's system, and found it helpful to be brought together."

Another training activity that the council participated in was the sponsorship of a downlink site for a national teleconference that was organized by another network: the Oneida County Mental Retardation/Developmental Disabilities Coalition in Utica, New York.

In 1990, the Finger Lakes Health Systems Agency authorized a large number of new nurs-



ing home beds in its twelve county catchment area. Of the 800 newly designated nursing home beds, 37 were specifically earmarked for persons with developmental disabilities, and four nursing homes have applied for and received permission for these beds. In order to help the administration and the staff from these nursing homes to prepare for this clientele, the state's Developmental Disabilities Services Office asked for assistance from the Council and the training program to sponsor a series of three workshops, and to organize a staff exchange at the conclusion of the workshops. Over 90 people attended these workshops, and about 30 participated in the staff exchange. This staff exchange allowed professionals from an aging agency to spend half a day in a developmental disabilities agency and vise versa. For some of them, this was the first time they had ever set foot in a nursing home, an adult day center or a group home. It was a meaningful learning experience for all who participated.

The council members also felt the need to engage in an exercise designed to help understand each other's terminology, barriers to access in care, and gaps in the service delivery system. The group decided to use a case study method and to split up into three subcommittees:

- The first subcommittee consisted of service providers who were asked to design representative cases that would illustrate the array of problems encountered by their clients. They were asked to write-up five case studies, which focused on psycho-social issues, health concerns, residential or day treatment needs and leisure demands. The charge was to include enough information to develop a care plan.
- The second subcommittee consisted of service providers (a different group) who would assess the case studies and decide whether or not they could provide services to these particular individuals and if they were not, to identify the reasons why. They were asked to comment on the problems that they might perceive in accepting these referrals and what barriers they perceived for service delivery.

 The third subcommittee was to consist of planners who would be asked to determine what could or could not be done to alleviate some of the problems.

It took about six months to complete the case studies. Everyone involved found it an exciting and helpful exercise, and they were amazed to find that a fundamental confusion and misunderstanding existed regarding terminology, service systems, rules and regulations. Several conclusions were reached, including a need for training, uniform assessment tools, review of all specially funded projects, the promotion of coordination of care, the design of strategies to increase public awareness of these problems and the formation of a group of specialists to advise on difficult cases.

At the council meetings, members gave feedback about all of the activities that were occurring in Monroe County. They helped in troubleshooting for staff who ran the integration demonstration project, provided a forum for the lessons that were learned from the integration efforts in a medical model adult day care center. and responded to the call from the New York State OMRDD for suggestions for guidelines for program ingredients or requirements for a Medicaid Day program for seniors. They were asked to outline what might make such a program different from a similar program for younger adults. They gave thought to such issues as activities, special staff requirements, training needed and program content.

In order to respond to specific requests, such as data collection, or give feedback to OMRDD, the council divides into ad hoc subcommittees that work on a given task for a specified amount of time, report back to the council and dissolve their duties. In doing so, it usually became important to pull other people in, who in many instances expressed a desire to join the council. This meant that although the formation of the council had initially been a formal process with specific representatives from specific constituencies invited, the process became more flexible when different persons joined the group.



Currently the council meets four times a year, changes the location of the meetings to give people a chance to visit other programs, and focuses on networking, information sharing, advocacy and problem solving.

There are many other networks in aging and developmental disabilities in New York State; they all share information with each other, and send each other the minutes of their meetings. This is a helpful method to stay in touch. One of the plans we have is to sponsor a meeting of all the networks in the state to learn from each other what we are doing in our respective communities.

Lessons Learned

Professionals in the fields of aging and developmental disabilities can work together effectively.

In Monroe County there exists a great deal of enthusiasm and commitment to working together to promote the welfare of older persons, in particular the welfare of older persons with developmental disabilities. Typically, people who work in the field of aging know each other quite well, as do people who work in the field of developmental disabilities. However, as in other communities in the country, representatives from these two systems did not know much about each other's system, and found it helpful to be brought together.

A definitive approach is necessary for planning.

The approach taken to organize a formal consensus planning conference was helpful for a variety of reasons. First, it gave sanction to the process, as the original invitees were the agency directors, program administrators and high ranking government officials. Second, it brought a sizeable group of people together for a number of days which allowed for a great deal of networking. The conference was structured so that no formal presentations were given, but the services of a group facilitator were used to brainstorm, exchange information, discuss preferences and jointly agree on solutions to the various problems present-

ed. Third, it gave the impetus to continue to process and created a large network of people who otherwise would not have come into contact with each other.

As with any organization, leadership is crucial.

The steering committee of the council has been chaired by a member of the University Affiliated Program for Developmental Disabilities of the University of Rochester which had brought together the group initially. The initial appointments to the council's steering committee were made as an outcome of the taskforce. A formal process was used, with representatives from various constituencies invited to become members. Although this process had the advantage of official sanction, it had the disadvantage of excluding membership of some persons who had a vital interest in working with the group. There also was no mechanism to recruit these individuals later. Eventually, the rigidity of the group lessened and other persons were invited to participate.

Parting Comments

Every group needs a mission and tasks to keep its members productive. Although the overall mission remains the same, the experiences gained by the service providers who work with this population, the obstacles they encounter and the solutions they find to surmount these obstacles become increasingly varied and complex. Also, the knowledge gained in the past few years of successfully integrating aging persons with developmental disabilities into the community forms the base of increasingly sophisticated discussions which need to be shared with the community.

Fiscal and budget concerns place great demands on the time which can be spent with service recipients. Due to the current fiscal climate in Monroe County and in New York State, service providers have greater demands on their time to provide direct service and less time available to attend outside meetings and training sessions. This problem has prompted the Monroe council to limit its meetings to four times



per year, with the understanding that special meetings can be called on an ad hoc basis.

From our experiences, I would offer the following recommendations:

- Open membership to all interested parties in the community.
- Rotate sites for meetings to permit members to visit each other's agencies.
- Share mailing costs, taking of minutes, and logistical responsibilities.

- Allow time for information sharing.
- Link meetings to educational programs.
- Share leadership, and consider co-chairs for a council.
- Ask council members to perform specific tasks and report on them on a regular basis.
- Consider minimal membership dues.

Oneida County Aging and Mental Retardation/ **Developmental Disabilities Coalition**

Kathleen M. Bishop, Angela Z. VanDerhoof and Ronald Lucchino¹

Case Abstract: This case study describes the evolution and workings of a coalition of developmental disabilities and aging network agencies that came together to plan, advocate, and promote systems change in Oneida County in upstate New York. The coalition arose from an effort to define the needs of the county's population of seniors with developmental disabilities and evolved into an interagency workgroup. The coalition members found that their partnership arrangements helped to promote training, program development and greater interagency cooperation.

Introduction

The Oneida County Aging and Mental Retardation/Developmental Disabilities Coalition has its roots in an interagency effort which began in 1986 to address the issues related to Oneida County's population of aging individuals with developmental disabilities. The original task force was comprised of representatives from state, voluntary and local agencies in both the aging and mental retardation/developmental disabilities networks who came together to assess the demographics of Oneida County's

population of older adults with developmental disabilities.

Oneida County, located in New York's Mohawk River valley, has a population of 250,000 people. Its major city is Utica. It has a range of agencies including the Association for Retarded Citizens (ARC), an independent li ing center, state developmental services agency, state psychiatric facilities, as well as its own area agency on aging, and a college with a gerontology education program.



Correspondence should be addressed to Kathleen M. Bishop, M.S., Rome Developmental Disabilities Service Office, Box 550, Rome, NY 13440; Angela Z. VanDerhoof, Oneida County Association for Retarded Citizens, 14 Arnold Avenue, Utica, NY 13540, or Ronald Lucchino, Ph.D., Institute of Gerontology, Utica College of Syracuse University, Burrstone Road, Utica, NY 13502.

As a result of the initial work of the taskforce, a report, The Newest Minority: The Aging Mental Retardation/Developmental Disabilities Population in Oneida County, was published in 1988. The report provided background statistics and an overview of the local issues. An extensive list of recommendations was provided on specific methods to reduce barriers as well as strategies to promote systemic integration. One of the outcomes of the taskforce report was the establishment of an interagency coalition in 1989, which included members of the initial taskforce as well as representatives from other agencies.

Project Description

Because the original task force grew in size and complexity, it was decided to organize a steering committee and appoint working sub-committees. The steering committee was charged with the responsibility of guiding the larger coalition by establishing issues and agenda items for the coalition meetings. Both groups met on a quarterly basis within Utica.

Subcommittees were developed in the areas of Professional Education, Community Education, Special Events, Integration and Fundraising. The chairs of each of the committees serve on the steering committee, report to the Coalition, and guide their committees in addressing the recommendations of the original task force. The subcommittees also meet on an ongoing and as-needed basis.

Empowerment for the Coalition was handled via a memorandum of understanding (MoU) that was signed by the directors of the region's state developmental disabilities office and the Oneida County Office for the Aging. The MoU assigned the coalition as the oversight body. Additionally, the executive director of the Oneida County ARC, served as a co-chair and provided extensive resource support and the director of the Oneida County Office for the Aging served as an active member of the coalition.

The Coalition has accomplished many of its original goals and continues to expand its scope of activities. The Coalition:

- Held two series of ten-week cross-training sessions -- topics included Network Overview, Psychology of Aging, Overview of Developmental Disabilities, Recreational Activities, Biology of Aging, and Environmental Design for the Aging.
- Sponsored a series of national teleconferences on aging and developmental disabilities, including one in 1991 titled, Bridging the Networks: Dignified Alternatives for People who are Aging and Developmentally Disabled. This conference had 46 downlink sites in 23 states with over 2,000 participants and was cosponsored by the University of Rochester Training Program in Aging and Developmental Disabilities.
- Initiated a statewide search for unidentified older people with developmental disabilities through an electric company's bill supplement.
- Sponsored ongoing advanced training workshops on such topics as Premature Aging, Down Syndrome and Alzheimer's Disease, and Activities Planning.
- Guided integration projects with senior centers, nutrition sites, and senior activities in the community through the formation of an integration committee that promoted integration of services between networks and providing assistance.
- Awarded annual Emily Oliver Scholarships for undergraduate or graduate training in aging and developmental disabilities.
- Sponsored the annual Emily Oliver Award for staff and volunteers who have provided outstanding leadership in serving persons who are elderly and have a developmental disability.



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- Applied and received a grant for a joint Oneida County Association for Retarded Citizen (ARC) and Resource Center for Independent Living (RCIL) supportive retirement program.
- Promoted staff exchange days among Coalition agencies.
- Heid numerous local, state, national and international conference presentations with both networks represented.
- Produced a twenty minute video, Side by Side, that describes the Coalition's work.

All of the Coalition's activities enabled the bridging of networks and were designed to increase the knowledge base, expand awareness of the issues, and impact the attitudes in both networks and the community.

Lessons Learned

Cross-training is a valuable tool for bridging the networks.

Cross-training of both networks provides a common knowledge base which gives information from different viewpoints encouraging the co-presenters to work closely together. The topic, Overview of the Aging and Mental Retardation/Developmental Disabilities Network, is especially suited to co-presentation. Training is often viewed as neutral territory and is an excellent starting point for coalition building.

Involving a university center or local college provides additional resource and credibility to the training.

Part of our success with coalition building was attributed to the membership in the coalition of the Institute of Gerontology at Utica College of Syracuse University. Two members of the coalition also served on the executive board of the University Affiliated Program in Developmental Disabilities' Training Program in Aging and Developmental Disabilities at the University of Rochester. Both of these affiliations provided expert

training and grant funding resources that would not ordinarily have been available to a coalition.

To "bridge the networks," a coalition should be as broad-based as possible.

Both the aging and mental retardation/developmental disabilities networks should be broadly represented. Agencies such as the state mental retardation/developmental disabilities and aging offices, local ARCs, nursing homes, social day care programs, local colleges and universities, United Cerebral Palsy and senior citizen centers should be represented. The more ownership the participating agencies take in the coalition's activities, the more successful the coalition is likely to be.

A coalition's activities should be approached with a sharing attitude.

During scarce budgetary times, human service agencies may find it difficult to serve new populations of people. Often the fear is that by adding new people the consumers already served will lose services. Emphasis needs to be placed on the sharing of resources and the expertise between the networks. All older people can benefit from this sharing. Such resources as trainers, equipment, supplies, activities, transportation, staff and physical sites can be shared.

"Reverse" integration is a very effective approach to bridging the networks.

Inviting seniors from the community to activities and programs held by the mental retardation/developmental disabilities agencies is a very effective way of bridging the networks. A coalition becomes an enabler, fostering the reverse integration. Participation in activities conducted by the mental retardation/developmental disabilities network helps the community to feel more comfortable with people who have developmental disabilities and is often a way to ease fears that are based on lack of familiarity.



Bridging networks should take place prior to integration.

The integration programs sustainable over long periods of time are those where staff bridging took place prior to the implementation. The staff work together through barriers and issues, looking at the program as their mutual domain, rather than a "we-they" approach. A coalition can facilitate the bridging of specific programs.

Strong support by key administrators of agencies participating in the coalition will enhance coalition activities and integration projects.

The key administrators of the agencies participating in our coalition provided strong support to the coalition's goals and activities. Much of what has been accomplished could not have been accomplished without the administrators' support, especially in the area of resource sharing.

In our case, this support was formalized through a memorandum of understanding signed by the directors of the region's state developmental disabilities office and the Oneida County Office for the Aging -- the area agency on aging. The MoU assigned the coalition as the oversight body.

Systemic integration overseen by a coalition is much more effective than fragmented activities.

Bridging entire networks (systemic integration) means that integration as a way of operation for agencies is sustainable and operational. Oppositional, fragmented activities may have short term life expectancies based on the length of funding. Systemic integration means that resources are shared.

Networking is the basis for program planning and funding does not drive the program development and implementation. Fragmented activities are often activity specific. If the funding is out, the activity ceases. Systemic integration limits the occurrence of this short-term programming process and encourages integration as a philosophical base.

Staff exchange poortunities promote integration activities.

Providing staff opportunities to visit sites in the other network is an effective method ofeducating staff about each other's system. These opportunities enhance systemic integration and joint program planning. Often, just knowing the contact person to call when there is a question or an issue about the other system makes a difference.

The establishment of a bridging committee by a coalition can enhance integration efforts.

Establishing a committee whose focus is on integration will encourage integration between the networks. The committee is charged with matching people and potential senior placements as well as working with staff from both networks to ease fears.

Strong leadership is important for a successful coalition.

Strong leaders, who help to spark interest in bridging the networks, are needed. It works extremely well if that leadership comes from a variety of agencies in both systems. This diversity maintains and fosters ownership in both networks.

Parting Comments

The Oneida County Aging and Mental Retardation/Developmental Disabilities Coalition is extremely proud of its accomplishments in successfully bridging the networks. Symbolic of the success in bridging the networks is the personal friendships that have been developed across agencies and networks. These friendships help to cement the ongoing relationships between agencies and assure that planning for people in Oneida County who are aging and have developmental disabilities is done within a climate of cooperation.



ection 2: op Down Efforts

Some efforts begin with "top down" or state level planning and development. These efforts usually result from the recognition that some problem or void exists and of the need to develop a means to address it. Many such efforts are demonstrations where the state attempts to test out one notion or another. Other efforts are done in concert with a reliable local agency which is asked to try a project and help the state test out an idea.

Several of the case studies we came across were in this category. Although the examples cited involved an agency that carried out the initiative, the impetus for it came top down from the state. In such situations, a request for proposals (or RFP) method is generally used to select the participating agency and support monies are awarded on a time-limited basis to either test out an idea or pilot the project to get it started. Other times it is done by contract or by the state as its own provider. Usually, operational monies follow so that the agency can continue the initiative.

In most instances, such efforts are designed to address a particular problem, as is seen in the examples in this section. For instance, one prevalent problem is the need to provide services to seniors living in rural areas; another is stimulating greater retirement options. Yet another is expanding housing opportunities. The examples of the Delaware, Kentucky, New York and Rhode Island efforts show how public policy changes and good ideas can grow to become effective service responses. Utah's example shows how a state program development effort, in the hands of an innovator, can help shape a broader public policy.

The lessons learned? One certainly is that the state has the capacity and resources to stimulate program development as well as the ability to aid in accessing existing services. In this regard, "money talks;" grants and other allocation of resources can go far to make projects like these work. Another lesson learned is that problems, however seemingly insurmountable, can be overcome with creative management and good, reliable people. As with other examples throughout the casebook, the participation of a key person, a "spark," has helped to make such projects work. In addition, state efforts must allow for flexibility so that innovation can emerge. Lastly, if the state stimulates such efforts, it can bring a degree of leverage that often is unavailable in other situations. State level agreements, or interagency activities, can force or influence cooperation at the local level among providers reporting or accountable to the state agencies.

First State Senior Center

Marianne Smith and Roy Lafontaine1

Case Abstract: This case study describes the experiences of the State of Delaware's Division of Mental Retardation in developing a senior center day program of a group for seniors with mental retardation in one region of the state. The state agency was able to start up and maintain a senior program that served to aid its participants with transitioning, volunteering and using other community aging network resources. The project found that some difficulties did occur in managing the transition and that a generic senior center environment was not always able to meet the needs of all the seniors using the program.

Introduction

During the late 1970s, Delaware state agency staff realized that many of the state's older adults with mental retardation would need a senior center they could attend with their same age peers and participate in activities that would meet their needs and interests. Our elderly population of persons with mental retardation consisted of many adults who had once resided in our state institution, but were beginning to move into various community residential options and attend day habilitation programs.

We found that age appropriate community skill teaching became necessary and that integration needed to be congruent with the community inclusion and citizenship experienced by age peers already living as members of the community. With adequate social skill learning, the seniors with mental retardation would be able to become members of established senior citizen programs designed to serve any and all senior citizens.

Thus, was born a project that would lead to the development of a senior center program for those seniors who needed a transitional environment to learn social and other skills that would aid them in being full-functioning "senior citizens."

Delaware, called the "First State" because it was the first to opt into the newly formed United States, is somewhat of a unique state, both because of its geographical location and small population size. There are two mental retardation service regions. However, most of the se-

niors with mental retardation are in the Kent/Sussex Region which comprises the southern two of Delaware's three counties. In addition, because of its small size, Delaware's state unit on aging, the Division on Aging, is also the area agency on aging.

Project Description

In the early 1980s, because of the limited capability of our local senior centers to absorb older Delawareans with disabilities, we decided to develop a senior center-type program under the auspice of the Division of Mental Retardation. Thus, in 1983, initial funding was requested for the development of a model program for Delaware's senior citizens with mental retardation. This modest budget request (some \$40,000) provided contract funds for the development of a program site, but did not contain money for staff lines or operating expenses.

Even though we had monies to underwrite the costs of a center, to begin the project we had to borrow staff and operating resources from other state programs. Thus, once the appropriation was approved, division and regional staff worked, planned, researched, and did whatever was necessary to develop a program that would provide an environment to assist in teaching seniors about all aspects of community life.

Our goal was to aid a number of seniors within the Kent/Sussex region to retire and move into more age appropriate programs. We envisioned a senior center site that would be the heart of a range of activities to which the seniors



Correspondence should be addressed to Marianne Smith, R.N. and Roy Lafontaine, Ph.D., Delaware Health and Social Services, Community Mental Retardation Programs, Route 1, Box 1000, McMullen Building, Georgetown, DE 19947.

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would come and then from which the seniors could go to learn and use more of their community. A site for the center was selected in Milford and we began to recruit seniors.

To begin, thirty older adults were selected from a number of adult day habilitation programs operating in the Kent/Sussex Region of Community Mental Retardation Programs, one of two of the Division's community program arms. As each individual was referred, an assessment was completed and an individual program was structured that was functional, yet relaxed. The individual programs were geared to provide stimulation, maintain independent living skills, stress health and nutrition, promote social interactions and cooperation, provide exercise as well as leisure time, and most importantly, to promote selfesteem and reduce feelings of dependency upon others.

On July 5, 1988, the First State Senior Center became a reality. Support from the Secretary of the Department of Health and Social Services and the Director of the Division of Mental Retardation was overwhelming. Their willingness to meet with anyone and everyone to get the "ball rolling" was essential to the success of the pro-

The overall purpose of the First State Senior Center program was "to recognize the unmet needs of elderly persons with mental retardation and to develop services for them that are more in accord with the goals and requirements of the aging population within the community." One of the major goals of the program was to prevent segregation of elderly citizens with mental retardation through the promotion of integration in established community programs serving the senior population. To this end, we also set up a retirement assistance program that helped the seniors who attended the First State Center to become acclimated and use a variety of generic resources and amenities in our region.

As more seniors were transitioned through the Center (about 30 a year used the Center) we saw the senior program growing and developing methods of assisting handicapped individuals to participate in a full community life and to expand their social horizons. One way was through enrolling some of the seniors in volunteering programs.

For example, some 23 of the seniors who currently attend the First State Senior Center are retired senior volunteers with the local community Retired Senior Volunteer Program (R.S.V.P.). They work within the pediatric ward of a local hospital, developing small projects and kits for the children to use while recuperating, and they work in a horticultural project to help beautify a local park.

We also developed a senior companion station at the First State Center and found that this was one of our most productive endeavors. During the past five months, senior companions have volunteered over 3,500 hours of their time to help our seniors in many of the programs at First State Senior Center. They have also assisted with transportation and with a variety of community integration efforts.

While our center program was quite successful, our initial overtures to local senior centers were not that productive. In the early stages of the First State Center program, we tried to make connections with local senior centers, but we found that a number of them needed special intervention from senior management officials to open up their activities to our seniors. With time, however, the seniors from the local community senior centers have gradually become involved with our unique center and have extended a welcome to have seniors from the First State Center to become part of their centers.

On any day, the First State Senior Center serves approximately 35 seniors with mental retardation who may live within a forty mile radius of the center. However, we have about 50 seniors who consider themselves members of the center and who attend at one time or another. The center's staffing includes three full-time workers, three part-time staff, and a number of volunteers. Preservice and ongoing inservice training is provided to all staff.



Lessons Learned

New programs can evolve from creative reallocations of existing fiscal and personnel resources.

Delaware has learned that by reallocating monies to develop community resources, it could develop a program that could start from scratch and be built into a viable senior program resource with its own budget. State top down budget and resource support was crucial to getting this project going and to keeping it sustained.

While ensuring safety and well being of participants, the program must be as free as possible from the cumbersome regulations and standards that normally govern operations of and can inhibit innovation in habilitation programs.

The freedom to let a program model evolve unencumbered by traditional and regulatory demands means that staff can be creative and develop a program that will be responsive to the needs of its participants.

The use of volunteers should be an integral part of planning for a seniors program.

By involving other seniors as volunteers, particularly through programs such as R.S.V.P. and Senior Companions, you enhance the capabilities of seniors with disabilities to have role models and expectations for opportunities for community involvement.

Comprehensive public education, conducted by well-qualified developmental disabilities professionals is the key component of an effective and efficient process of aiding transitions to generic aging network programs.

We found that in some instances we had to provide encouragement to the senior center personnel and members to be more accepting of integration efforts by public presentations and special meetings. Professionals in the field of developmental disabilities are well equipped to take an active part of such education of the community. Participation in conferences and other functions hosted by generic

aging agencies was helpful to us to get the "message across." With continued education and other forms of networking, we found that receptivity eventually led to acceptance.

Flexible program hours and transportation schedules facilitate continuous participation of seniors.

To make optimal use of our center, we found that it was important to set up the mechanisms for the seniors to be able to get to the center. To model the use of community centers, we taught them that Center activities were at their disposal, but that they had choices and that they had to provide input to the decision whether or not to participate.

Parting Comments

The First State Senior Center is a dream fulfilled. It is growing and reaching out to the various communities in two of Delaware's three counties and program activities continue to increase. We have now helped twenty-three seniors successfully transition into generic community senior programs. We have found that people are working together to meet the needs of the Delaware's seniors with mental retardation.

In order to serve more people, plans are underway for the implementation of another senior center, which is based on the premise of First State Senior Center, in order to serve more people. We have also found that for some seniors the activities at the Center are too unstructured and we are making plans to develop a social model day care program.

In retrospect, the successful establishment of the First State Senior Center was the end result of years of creative planning and dedication to a common purpose. The individuals who contributed to this success are too numerous to mention. Yet, the fact that senior citizens with mental retardation now enjoy an improved quality of life in Delaware is a tribute to those people who are determined to keep the vessel of hope overflowing in the First State.



Kentucky's Rural Assistance Project

James A. Stone¹

Case Abstract: This case study describes the experience of the Kentucky Division of Mental Retardation in stimulating rural services development for older individuals with mental retardation in Kentucky's Mason County area. The Division worked through a rural developmental disabilities agency to open up existing rural senior and social services through the use of a services development coordinator. The result was a five county rural area which provided greater access to senior and other social services.

Introduction ·

Elderly persons with mental retardation who live in rural areas often have not had the same opportunities to participate in their community's basic socialization, education, recreation and support services that are open to other seniors (or younger persons with a handicap). This case study describes the development of a special effort that was targeted toward enabling seniors with mental retardation living in a rural area of Kentucky with accessing their community's aging network services. It also illustrates the effects of the program upon two individuals.

The state of Kentucky has a diverse population. However, according to the Kentucky Economic Handbook, some 80 percent of the state's citizens live in rural areas and some 15% of its population is elderly. Traditionally, the state's rural areas have not developed adequate services or programs for individuals with mental retardation.

As one of its concerns, the State Division of Mental Retardation began to investigate the needs of the state's older population of persons with mental retardation. One of the questions raised was: Does Kentucky have an elderly population with mental retardation, and if so who and where are they? Older persons with mental retardation, in the broadest sense, were defined as: "older citizens who were unable to read, could not write, and lived at or below the poverty level."

The Division's inquiries determined that only a small number of individuals with mental retardation over age 60 were in community service programs. It also found that the four state-

owned ICF/MR facilities served only 11 seniors age 60 or older, the five private facilities served only 15, and the one private school served 28. Further, an additional 340 seniors with mental retardation age 60 and older were found to be residing in nursing homes across the state. The 14 regional mental health/mental retardation (MH/MR) boards -- the designated regional planning authorities for the state's community based services -- served some 142 elderly seniors from across the state, mostly in the state's urban areas.

Thus was born a special project to improve outreach and access for Kentucky's seniors with mental retardation living in rural areas.

Project Description

In 1986, the Kentucky Division of Mental Retardation (DMR) funded a demonstration project for elderly individuals with mental retardation who resided in five rural counties along the Ohio River in northeastern Kentucky (an area of some 52,500 people). The selection of this region was based on the DMR's interest in providing new service options for rural seniors, locating a rural area that would provide an opportunity to dismiss some of the myths around the unavailability of services (such as transportation and recreation/leisure opportunities) and the inaccessibility of local senior programs, and finding a provider agency which had a high level of professionalism and enthusiasm among its management and the direct service staff toward taking on new projects. The DMR was also interested in starting a project in an area in which few seniors with mental retardation were being served. Because a prelimi-



Correspondence should be addressed to James A. Stone, M.S.A., Project Director, Interdisciplinary Human Development Institute, Room 330, Mineral Industries Building, University of Kentucky, Lexington, KY 40506-0051.

nary survey revealed that there were none, this particular region was ideal.

The major provider agency chosen to participate in this demonstration project was Comprehend, Inc., located in Maysville, Kentucky (a rural community of some 7,900 people), the county seat of Mason County. Although located in Maysville, Comprehend serves the surrounding five counties. The DMR gave the agency a \$50,000 program development grant that was to assist them with program development, outreach, and networking. The author, at the time with the Kentucky DMR, was the state project liaison.

The original plan for the demonstration project was to serve 10 to 12 older individuals with mental retardation in the one community. It was anticipated that a combination of generic services and funds from the grant would be used to support the participants in individualized programs. The expectation was that the grant would enhance and enrich each senior's choices and options to use available resources within Mason County. The available community resources included a regional medical center, a local health department, a public library, a community college, churches, two small shopping centers, a newspaper office, and a senior citizens center.

This particular community is the site of the offices of a number of the state's social service agencies for the region. Among these agencies were the Department of Social Services, the Area Agency on Aging and the Private Industry Council. The available transportation system consisted of a small taxi company and a city bus line.

Named the Kentucky Rural Assistance Project, the demonstration project was designed to be implemented in several steps.

Step 1 -- select and train a project coordinator. The person selected for the position had worked with many of the agencies in the community on advisory boards and as a volunteer for many years. Her experience proved to be invaluable later when it was

time to begin serving the target population.

Step 2 -- conduct networking and lay the foundation. About three months were spent sharing information with the established agency networks and exploring the steps to develop a working relationship for multidirectional referrals.

During the first three months, we worked to let Mason County's agencies know that the project expected to establish a working relationship with each participating agency in assisting the individual on an as-needed basis. However, early information and previous experiences in other programs indicated that elderly persons in general would not readily welcome peers with mental retardation into their senior centers. Thus, a plan was put into effect to provide socialization opportunities three days per week at the project office site. The site, located within the general facilities used by Comprehend, Inc., included a three room house (a kitchen, activity room and a reception area with couch and chairs) plus an office for the coordinator. The Comprehend, Inc. site occupied a building that was previously a nursing home. Thus, the Kentucky Rural Assistance Project created a temporary senior center for the use of the project participants.

Step 3 -- conduct an outreach effort to locate isolated or uninvolved seniors within the rural environs of Mason County.

Once a senior was identified and invited to participate in the project, a staff psychologist conducted an informal interview with the person and attempted to assess his or her needs and abilities. Interestingly, it was found that each person referred had no history of previous services from the agency, and medical records and family members were not always available to verify their history of mental retardation.

Part of the intake process consisted of assessing the abilities of each person, his/her current situation and living conditions, activities, interests, and medical/health condition. The project staff then created individualized activity



Mr. Alex C.

Mr. Alex C. is a large man who lives in a personal care home with two other individuals. He does not read or write, and is mildly mentally handicapped. Mr. C. has no family in the area. He never received any formal education and had not been a client of the regional MH-MR board. He has heart disease and wears a pace maker.

Mr. C. was 64 when he began participating in the project. When we first met him, his daily activity was to leave his home each morning and spend hours walking the streets of his community visiting any businesses which had extended friendship. Mr. C. pestered the community because he had nothing better to do with his time. He also spent a great deal of time at the health clinic because of his health worries. After initial interviews with Mr. C., we realized that he was getting adequate meals and supervision from his care provider, but needed some new opportunities and choices for spending his free time. Individualized programming included having lunch in the community's restaurants with the project coordinator and one or two other project participants once a week, coming to the project offices on a regular basis, and using the entertainment and recreational resources in his community. Outside opportunities included shopping excursions to Cincinnati.

Medical appointments were a problem for Mr. C at the beginning of the project. Now he has other activities to keep him busy and his mind off his health concerns. After five years of participating, Mr. C. is a member of AARP, is a five day per week volunteer at the senior citizen's center (he is in the VISTA program) helping serve the lunches, and spends his afternoons in another program which has eliminated his wandering the streets and the pop-in visits to the businesses. Mr. C. participates in the planned activities of our elders program when his schedule allows. He has been able to attend the annual county fair, a major social event for the area and one in which he never before had a chance to participate. Mr. C. has achieved a new level of activities which include interacting with age peers and being accepted in their social activities. Some of these activities include shopping at the mall and participating in the social events of the community. He goes to church weekly with a female friend and has become very involved in that relationship.

plans designed to provide the necessary support services and activities that would enable the senior to make choices and assess the options available to him/her. The goal of the project was to leave the participants in better positions than they would have been had they not become involved with the project.

During the early part of the project it became clear that we would not have open access to Maysville's senior center. We thus set up a project-run senior center program at the Comprehend facility site which we used initially for acclimation and as a stepping stone to the town's other social activities. However, the senior center was located across the parking lot from our project and overtime interactions between the project coordinator and the senior center director lead to the sharing of information about the needs of our project's participants. From this, the attitude of the center director changed. As a result, the senior center director invited the project participants over for lunch and then gradually invited them to participate in the center's activities -- thus achieving the integration that we had expected.

We found that by carefully planned communication and formal appointments with the various service agencies' management, we were able to set up a referral system that helped to identify seniors in need and get them into the services best equipped to aid them.

Step 4 -- expand the project's scope to the surrounding counties.

By the end of the first year, Comprehend expanded the project to all five counties. Currently, more than 150 individuals have been referred to the project which now has a capacity of serving 35 older individuals during any month and has activities in all five counties in the region. The average age of the participants is 74.5 years; the range is 55 to 91. The participants function in the mild to moderate levels of mental retardation; many have some age-related health problems (as would be expected in a rural, low income area); however, some 25% are free of any major medical problems.



Ms. Blanche M.

Ms. Blanche M. was a small, seventy-one year old lady who was thought to have mild mental retardation. She could not read or write, had never received any formal education, and had no previous history with the regional MH-MR Board. She lived alone in a public housing unit and did not have any living relatives. Although isolated in the community, she received some assistance with her mail and other personal business needs from neighbors.

The first contact with Ms. M. by the project coordinator indicated that she was a suspicious individual who was not sure if the project could do anything for her. Some years before, she had worked as a volunteer in the local hospital but had been "retired" as a result of poor personal hygiene. Because of her inability to read, she developed a feeling that socia! agencies were reluctant to provide assistance. After seventy-one years, she had grown bitter. However, she agreed to participate in the "elders project" on a trial basis.

Each week, Ms. M.'s participation in the project brought about more and more changes. Trips to the beauty shop to have her hair washed and set improved her self-esteem to the point that she enhanced her daily care. As a result of these changes, the project coordinator was able to get her back into the hospital volunteer program. Ms. M. participated in the activities, enjoyed the community lunch dates, and her volunteer work.

During the spring of 1987, she expressed an interest in gardening and growing flowers. However, the public housing had limited places for gardening. The "elders project" purchased bedding plants and provided space that allowed Ms. M. to garden after she had completed her shift as a volunteer. She also received assistance from the "elders project" in paying her monthly bills, getting around, dealing with other agencies, and making and getting to medical appointments.

In February 1988 Ms. M. died in the hospital where she worked as a volunteer. Her participation in the project expanded the opportunities and choices of activities she was able to enjoy during the last fourteen months of her life. She participated in the activities of the senior citizens center, the elderly project, and as a community volunteer. She developed new friendships and enjoyed more activities than she would have had she not made the decision to participate.

What has been the impact on the lives of the individuals who participated in the project? The first group included two persons, Ms. Blanche M. and Mr. Alex C. who, like many of the others, appeared to benefit greatly. Their vignettes attest to the success of the rural assistance project.

Lessons Learned

A state initiated project, backed by development funds, can have a beneficial effect on an area's ability to serve its seniors.

A state top down process can help stimulate local program development. However, it should be accompanied with adequate development funds to enable the agencies participating to carry out the project.

No matter how isolated people were, there was somebody in the community who seemed to watch out for their interests.

We found that all of the seniors who became involved in our project had a neighbor who was aware of them and seemed to look after them in some manner or another. This aspect was indicative of the nature of the rural community we chose to use.

The project coordinator worked individually with each agency, but it would have been better to have an interagency workgroup.

The project has assisted a number of the seniors in applying for and receiving assistance to which they are entitled which includes supplemental security income, food stamps, rent subsidies, weatherization and fuel bill assistance. Some of the people have been relocated from substandard housing. Although the project coordinator was instrumental in getting much of this done, it might have been easier and quicker if we had first brought together all the relevant agencies and got them involved in an interagency workgroup.

Having a petty cash fund was crucial to helping in emergency situations.

Sometimes just having small change to help

pay someone's electricity bill or buy some new shoes made the difference in day-to-day survival. We would highly recommend having some discretionary funds to address small outlays on behalf of the seniors. In this rural, low income area, the seniors often were very poor and had very limited resources.

Parting Comments

Our success hinged upon meeting the individual needs of each person and providing coordinated services, with subtle advocacy, that enab 1 them to receive all the benefits necesenhance their lives. The ability to develop friendships, have accessible transportation and be able to access the generic age-appropriate service systems within the community provided the seniors with the opportunity to make choices and to exercise options that were not being used for various reasons, including the inability to understand what is necessary to receive specific benefits and services. Our approach to making individualized needs determine most of the structure and makeup of programs and services seemed to work best.

Over the years, the project has networked

with more than 40 public and prigate agencies and service providers in the five counties. The first participants in the rural elderly project provided us with invaluable information and experiences that helped us expand the state's efforts to develop individualized appropriate services and programs in other rural areas. We were particularly concerned that each of the seniors could make choices as to what they actually wanted to do. The two seniors we chose to illustrate the project's efforts are only illustrative of all of the others. There were more than eighty additional life stories available -- they included two sisters and one brother and a mother and daughter who lived by themselves, and others who lived in mobile homes, nursing homes, board and care homes, personal care homes, on farms, or in public and senior hous-

If there is one lesson to pass along then it is that such state initiated efforts can work and that services in rural areas can be mobilized, accessed and made available for older adults with mental retardation living in isolated and rural areas.

Utah's Supported Retirement Program

Gerald J. Nebeker and Deborah O'Dell¹

Case Abstract: This case study describes a project in Tooele, Utah that began as a response to a state call for residential relocation projects. Twelve seniors were aided in finding apartments in the same neighborhood. The agency went on to aid in supporting daily self-directed program activities and aiding the seniors with integration as full participants in a local senior center and other community activities. This project was unique in its creative means of complying with accountability regulations, while being able to change state policies and mandates to accommodate an unexpected purpose.

Introduction

In 1987, a Request For Proposals (RFP) was

issued by the State of Utah, Division of Services for People with Disabilities to establish community residential programs for senior citizens with



Correspondence should be addressed to Gerald Nebeker, M.A., President, Residential Services, Inc., 1561 North Grandview Lane, Provo, UT 84604-1019 or Deborah O'Dell, M.S.W., Program Specialist Ajing/Developmental Disabilities/Mental Retardation, Division of Services for People with Disabilities, 120 North 200 West, 201, Salt Lake City, UT 84103.

mental retardation/developmental disabilities. At the time, Utah did not have appropriate programs to meet the needs of this population. Each of the individuals who were identified for these programs were living in long-term care facilities for the mentally retarded (ICF/MR) or other nursing homes. Many of the individuals had been residents of some type of institutional facility for most of their lives.

The sole purpose of the grant was to establish residential programs. Given the existing policy structure, it was the state's intent that the individuals referred would attend traditional workshop programs during the day. It should be noted that in Utah, at the time of this program's inception, a residential program had requirements and funding completely separate from day activity programs. It was more the rule than the exception for an individual to reside in a residential program run by one agency and attend a day activity run by another agency.

To illustrate this process, this case study will examine one contract that was awarded to develop a residential service for seniors to Residential Services, Inc. (RSI) -- an agency that provides programs to a rural part of Utah.

Once the contract was awarded, the staff of RSI met with each of the individuals selected for the program to determine their strengths, limitations, and desires. RSI's administrative personnel felt that a holistic approach was essential in order to best meet the individuals' needs. It was the consensus that these senior citizens, like all other senior citizens, should be able to retire and rest from their life's labor. Based on an individual interview with each of the program participants regarding his/her life's preferences, RSI proposed a model outside the existing policy structure. The model went beyond the original intent by including the day activity with the residential program as a total package. With some of the standard system reluctance, the state agreed and consented to pilot a holistic program that integrated both residential and day activities. This model eventually became known as "Supported Retirement."

Project Description

Tooele, Utah is a rural community with a population of 14,000 and although there are a number of individuals with developmental disabilities in that community, there were few programs to serve them. In awarding the contract, the state required that a program be established in Tooele. This requirement was in response to the lobbying efforts of the community to increase its service options for individuals with disabilities.

Twelve individuals were involved in the Tooele site: nine men, and three women. Their ages ranged from 55 to 76. Each had a diagnosis of mental retardation -- the range of mental retardation was mild to moderate. Many had some type of physical disability: one had cerebral palsy and was wheelchair dependent, one had left side hemiparesis, one had a visual impairment and two others had hearing impairments. Most had other medical conditions such as congestive heart disease, emphysema, diabetes and/or conditions incident to aging. One had a secondary diagnosis of schizophrenia.

In establishing the program several barriers needed to be overcome which will be detailed as follows:

Finding a Home:

- » Securing appropriate housing was not as difficult as anticipated. RSI approached a real estate agent who happened to be the owner of an available duplex. The agent referred RSI to another individual, who then purchased a HUD repossessed property especially to rent to RSI.
- The guarantee of monthly rental payments and the assumption of liability for damages was an incentive for the landlords to be very cooperative which was a surprise based on previous experiences with skeptical and sometimes bigoted landlords in more urban settings.

The individuals expressed a desire to live in their own apartments with one or two room-



mates: No more than three individuals were housed in any one apartment. The apartments were duplexes in relative close proximity to each other. Many of the individuals were able to have their own room and only shared a room if they so desired. Surrounding duplexes contained individuals and families whose income, life style, and age represented a cross-section of the general population of Tooele.

Fitting into the community:

These individuals were well-received in this neighborhood. Possible reasons may have been:

- The whole neighborhood consisted of rental units.
- The individuals were living in small clusters rather than in one large group home facility.
- » Various religious denominations took some of the individuals belonging to their respective churches "under their wing" and provided fellowship. This acceptance was unique to this rural program as RSI did not encounter a similar experience with programs located in more urban areas.
- Generic services were used such as shopping in the local supermarket, recreating in the same places, going to the same physicians, having hair done by the same barbers and beauticians as the rest of the citizens of Tooele. These activities exposed the community to all of the individuals with disabilities and established them as equal citizens of the community.

Direct experience is the best teacher, and it did not take long for this small community to have successful exposure experiences which resulted in significant attitudinal changes and greater support in general.

Making the day program fit the people:

The establishment of this component represented a significant challenge because of the lack of precedence in Utah for a

home-based model. A review of the literature also produced few such models. After battling with the definition of retirement, RSI's philosophy was that retired persons in the general population base their activities out of their home and engage in these activities singly, with a spouse, companion, or a friend. The only exception would be the relatively small amount of time spent in organized, senior citizen activities. It was concluded that other elderly individuals do what they want to do when they retire.

The key element in RSI's design was individual choice. The participants and staff met together to discuss the definition of retirement and what that means. The participants were asked what they wanted to do with their time now that they did not have to go to workshop. Coming from institutional backgrounds, personal choice was not something with which they were familiar. It took some time for them to feel comfortable in making their own decisions and coming up with ideas. The staff made suggestions and created the opportunity to expose these individuals to different activities. Eventually, they began to take a more active part in choosing their activities. They began to think creatively about crafts or activities in which they wanted to participate. The activities were communitybased and the participants chose which crafts they would engage in while at home.

Making the program meet state requirements:

» The state's requirements were the cause of some discussion among social service personnel responsible for auditing the program. As with non-disabled retirees, as their health and energy decline, they often take naps during the day. What would happen if a federal auditor came in and observed one of the participants taking a nap? It was decided to have each of the participants get a physician's prescription for rest, PRN (as needed), to meet the letter of the policy requirements.



Policy traditionally required documentation of progress or retention of skills which posed a problem when the program allowed individual choice to the degree that it did. For example, some of the individuals wanted to volunteer some of their time to work in a local food bank for the homeless. Others wanted to devote several hours each week for church work. Others bought goldfish, resold them at a county fair and raised enough money to take a trip to Idaho to visit Yellowstone National Park.

Lessons Learned

The best way to meet the requirements should be to document progress or retention of skills based on skill categories rather than on specific activities.

It did not make much sense to develop a program plan specifically for selling goldfish or for going to Idaho. It made much more sense to consider selling goldfish and going to Idaho as methods of increasing skills in a broader categories. The categories selected for the program were community integration, leisure skills, behavior skills, communication skills, gross/fine motor, self-care skills, home living, and money management.

All activities were classified into one or more of these broad categories. RSI staff documented the type of activities chosen, how the individual performed, interventions and instructions necessary to accomplish the activity, and completed monthly progress notes for each category. This approach met the needs for funding accountability, but also allowed for the individualization desired.

Resistance or adverse reactions at a senior center can be overcome.

Attending a senior citizens center is an important activity for many retired individuals, however, RSI encountered significant resistance from the membership of the local senior citizens center. Two individuals began attending the center and did so without incident. No one knew they had mental retardation. Then RSI approached the center director to request that others with more visible disabilities be allowed to attend. He was very supportive and took the request to the cen-

ter's board which brought it to a vote. They voted to limit the "retarded" individuals' attendance. They communicated fears and misconceptions which from an outside perspective seemed rather trivial. For example, one of the reasons given for limiting access was that the "retarded individuals would call 'Bingo' out of turn" if allowed to attend and participate.

We decided not to challenge the senior center but rather to continue the program approach already begun. After a few months, the senior center asked if some of their patrons with Alzheimer's disease could join with the Supported Retirement group as the activities were more stimulating and interesting than the senior center's. Some of the individuals with Alzheimer's disease happened to be spouses of senior citizen board members which eventually led to a positive perception from the senior center's membership.

Parting Comments

Our efforts were a good example of how a laudable state effort was expanded and became the focus of innovation. We were able to secure housing, develop and help with using a range of day activities options, and "crack open the door" at our local senior center. The senior center option was not an easy one at first, but, eventually full-integration was allowed. At first, the Supported Retirement group was completely segregated at lunch and in all activities. Eventually, as both groups got used to each other, segregation gave way to full integration. Now it is virtually impossible to distinguish "who's who" as friends simply sit by friends regardless of disability. To illustrate, the basement of the center had pool tables which were "sacred ground" to the men that bought and placed them there. No one played pool except for those few men. As acceptance increased, the men eventually insisted that one of the pool tables be moved upstairs to accommodate a supported retirement individual who was in a wheelchair. The whole process took three years to achieve, two years before the senior center could be fully utilized and another year before full indistinguishable integration was achieved.



The following points are important to creating new efforts:

- It is important to stress similarities rather than differences when attempting integration into any existing non-disabled community program or group.
- Avoid paradigm paralysis -- how it is, is not how it has to be. Be willing to "take the heat" to make the necessary changes. A program will be successful only if it is based

on people rather than policy.

- The best methods of ameliorating prejudice are through education, experience, and exposure.
- Although legal means could have been sought to force attendance in the senior center, patience, compassion, and understanding of the community and their growth process paid greater dividends in the end.

New York's Senior Day Programs

Sharon A. Bradbury and Matthew P. Janicki1

Case Abstract: This case study describes the efforts of New York State's developmental disabilities agency in developing a series of model senior retirement programs based upon social model day programs. Through several competitive RFPs, the agency chose 31 programs, from within both the aging network and the developmental disabilities system. Following three years of operation, six initial programs are serving some 270 persons and an additional 25 programs are serving some 340 persons in a variety of settings and under various conditions. With the flexibility that comes from new monies and regulation-free program development, providers can be creative and innovative in designing new programs and offering retirement opportunities.

Introduction

Recognizing that the population of older New Yorkers with developmental disabilities is expected to increase throughout the next two decades, and anticipating the transition of individuals currently attending vocational and habilitation programs who desire "retirement" options, the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) and the State Office for the Aging (SOFA) sponsored a series of demonstrations supporting the evolution of senior retirement programs for older individuals with developmental disabilities.

Prior to this effort, the two agencies, with funding assistance from the state's developmental disabilities planning council, had overseen a series of feasibility projects that looked at how to adapt the aging system's programs to meet the needs of older New Yorkers with a developmental disability. These feasibility projects showed that older adults with developmental disabilities could be successfully integrated into generic community aging network programs, such as senior centers and congregate meal sites, and into specialized community aging programs such as adult day care.

After the feasibility projects were completed, OMRDD and SOFA decided to develop additional social model adult day care programs



Correspondence should be addressed to Sharon A. Bradbury, M.S.P.A. or Matthew P. Janicki, Ph.D., New York State Office of Mental Retardation and Developmental Disabilities, 44 Holland Avenue, Albany, NY 12229-1000.

under OMRDD's auspice. The feasibility projects had shown us that it was possible to aid seniors with developmental disabilities in using local aging network resources. However, they also showed us that for those older adults who were unable to use senior centers, there was a need for more adult day care type programs. Such services, it was reasoned, could not only meet the needs of the state's seniors with developmental disabilities, but could also serve older adults with similar functional impairments who needed a supervised day program.

Thus was born a new initiative to develop senior day programs. This development was based on the following assumptions:

- Continued labelling of persons as "developmentally disabled" into advanced age served no programmatic purpose.
- The State was moving in the direction of universal adult day care for the elderly in accord with the Governor's Long-Term Care Policy and Coordinating Council.
- Although many of the county offices for the aging did not yet fund social model adult day care, several were interested in joint ventures with OMRDD.
- Although most OMRDD day programs for seniors were in a Medicaid funded day treatment category, most older adults with developmental disabilities did not require such intense day services.
- Since not all seniors with developmental disabilities could readily blend into existing senior centers, a new day program model was needed that would offer a transition service and also meet the "retirement" needs of more cognitively impaired older persons with developmental disabilities.

New York is a large state in terms of it geography and diverse in terms of its population. Of its close to 18 million people, 17% are over the age of 60. With regard to the aging network, there are 59 area agencies on aging, almost equal to one per each of the state's 62

counties. It is estimated that there are some 12,000 older New Yorkers with a developmental disability, many of whom could be users of aging network or specialized senior day programs.

Program Description

As a result of enabling legislation passed in 1988, initially six senior day program demonstrations were funded. Interested agencies were identified through a request for proposal (RFP). The models chosen for funding were to be designed in a way that would assist older persons with a developmental disability to move from a Medicaid funded day treatment or state funded day training program into a community-based program that would have a retirement focus and be integrated within the aging network.

As a result of the RFP, a large number of excellent applications were received from around the state. From this pool of applications, grants were awarded to six agencies which began their programs in the fall of 1988. The agencies chosen each established a senior day program open to elderly persons with developmental disabilities. Five of the demonstrations were operated by disability agencies (one each in Erie, Steuben, Sullivan and two in Queens counties) and one by an aging network program (in Chautauqua county).

These initial senior day program demonstrations were built upon the social adult day care model, and as demonstrations were regulation-free. The focus of these programs was on socio-recreational activities and on more devoted staff/participant interactions. This design allowed seniors to be able to choose from a range of age-appropriate activities offered in a relaxed and comfortable setting. Much of the focus was on variety and choices, with both intra- and extramural activities involving community amenities.

During the course of their development, the projects were visited by OMRDD central office staff and state field staff and offered technical assistance. The central office staff also held a



cluster meeting, drawing together the staff of these projects with others who ran similar senior programs. Training was also provided through the aging and developmental disabilities training center at the University of Rochester. Concurrent to the demonstration development, special efforts were made to develop local network groups whose members could assist each other and share referrals and program practices. A number of such groups evolved around the state.

By the summer of 1990, the demonstration sites were serving 270 older adults. The average number of persons enrolled per program was 45; the smallest program had 15 and the largest program has 118. Not all participants attended each day. Most of the seniors were between 51 and 79 years of age; about half were in the 60 to 69 age group.

"Although many seniors will have the autonomy and capability to attend senior center activities of their own choosing and be involved in other retirement activities, others may need settings that provide more structured opportunities and activities that are to their liking and level of capability."

The one aging network program, operated by the Chautauqua County Office for Aging, served about 45 persons, eight of whom were seniors with a developmental disability. Originally, this program started out serving only three seniors with developmental disabilities. Three of the programs served seniors without a developmental disability who required adult day services.

The number of paid staff per program varied from one program setting to another, ranging from 2 to 13. The average was 6.3 staff per program. The staff/senior ratio ranged from 1:4

to 1:10. Besides the paid staff, five of the programs used volunteers from a variety of sources. The number of volunteers in the programs ranged from 3 to 13, with an average of 6.8 per program. Volunteers came from a variety of sources, including OMRDD's senior companion project, the Retired Senior Volunteer Program (RSVP), Green Thumb (a federal stipend program), and independent volunteers.

The types of activities available at each of the senior program sites varied. However, the pervasive philosophical theme was that individual participants should have the ability to choose from a wide range of activities offered in a friendly and comfortable atmosphere. Community amenities and services were tied in whenever possible to enable the seniors to feel as an integral part of their community. Some of the seniors even became involved in volunteer activities in their communities.

Common program features included health and sensory assessments, recreation and social activities, exercise and physical fitness, and reminiscence and group discussions. Depending on the location and availability of community resources, participants had the opportunity to interact with other elderly individuals. Some participants were involved in exercise and fitness classes for the first time in their lives. Extramural recreation activities encompassed community field trips to such settings as parks, museums, shopping centers, and concert halls. Some intergenerational activities with child care settings, and cooperative programming with community senior centers also took place.

The senior day programs were sited in a variety of settings. The two downstate programs, located in the borough of Queens, occupied space in buildings designed to provide a range of other services to individuals with developmental disabilities. The four upstate sites were in a variety of towns and locations. One used the social rooms of a Salvation Army chapel; another was located in a free-standing building in a small village. Another was colocated in a building with other programs serving individuals with developmental disabilities.



The one aging network program in a rural county had two sites in church social halls.

In 1990, after an evaluation of the six initial demonstrations, we were able to secure additional funding from the legislature for a considerable expansion. The issuance of another RFP drew a considerably larger response. From among some 40 applications, 25 new programs were selected for funding. This time 15 of the 25 new programs were in agencies associated with the aging network; the balance were in developmental disabilities provider agencies. Together, these 31 programs were now located in 28 of the state's 62 counties and served some 317 seniors. The programs were located in a variety of sites, including free-standing buildings, churches and synagogues, within generic service program buildings and in senior centers.

Comments from Program Directors

"Like other retirees, our seniors enjoy volunteering in various community programs. Four seniors deliver Meals-on-Wheels to "shut-ins" in their neighborhood once a week. The Meals-on-Wheels program is short on volunteers and can count on these individuals. The seniors and "shut-ins" have now gotten to know each other by name. They are dependent on each other and have become friendly."

"Some of the seniors have developed ageappropriate interests and capabilities they did not have before. For example, learning to play the piano, doing crafts as a hobby (both at and away from the senior day program), and developing and pursuing an interest in salt-water fishing. Two senior day program participants now go fishing with the members of their family care home on weekends, carrying over the skills and joy derived from fishing trips with their senior day program."

In 1992, an another RFP was issued based upon funding for an additional 164 senior program spaces. This time, however, the RFP not only called for applications for new senior day programs, but it also included a call for

retirement assistance projects. These projects served to round out the options being developed by the State. Not only was there an increased availability of adult day care type programs -- the senior day programs -- but there were also funds to aid seniors in enhancing their retirement by retirement coaching, aiding in using amenities of their choosing, and becoming more a part of the senior community.

Lessons Learned

Such programs seem to meet the needs in areas where social model day care is not available, or where health day care programs are the only option.

A range of options should be available to aid seniors with a developmental disability. Although many seniors will have the autonomy and capability to attend senior center activities of their own choosing and be involved in other retirement activities, others may need settings that provide more structured opportunities and activities that are to their liking and level of capability. We found that we should expand this program model to other areas, particularly to those without adult day resources or where the proportion of seniors is above the state average.

Although turnover was relatively low, continued training is still important, particularly as more programs serving seniors come on line.

We did not observe a great deal of turnover among the staff who worked in the demonstration projects. One manager commented that while his staff were quite experienced at what they did, he missed the ability to turn over staff and the new ideas that came with that. There was agreement that expanded cross-training of both aging and developmental disability providers would be helpful. We found a natural pool of technical expertise within the state's university/college and community college network and often drew upon them as well as other agencies that provided programs for seniors.

Permitting demonstrations to run unfettered by rules or regulations can produce innovation.



We purposely did not ask the initial demonstrations to operate within any existing regulations to help promote innovation and experimentation. It was our feeling that programs for seniors were like "uncharted waters" and the operations should have the freedom to "sail where they wanted to." We later imposed some parameters and we found that the agencies themselves exercised some controls, however, in most instances, the staff did provide for novel environments.

Volunteers can prove to be beneficial to these programs because it keeps the costs down and offers age-appropriate role models.

Upon examination, we found that much of the low cost operation of the programs (they ran on the average about \$21/day) was attributed to two things: lack of costly regulatory requirements and the use of volunteers. Perhaps, our experience may be unique as we had access to a pool of senior companion volunteers, but we also found other types of volunteers thus telling us that the program operators were a resourceful lot.

Requiring maximum use of community amenities and relations with other senior programs has proved to be useful and beneficial.

It was our belief from the onset that we wanted as much exposure as possible to the community for the seniors using these programs. We asked each program to tie-in with existing community resources, such as social services and existing senior centers, and appropriate recreation and leisure activities.

Training and providing for networking are crucial to ensuring quality.

Some of the programs were set up without direct oversight by people skilled in senior services design. Upon visiting the programs, it was found that some needed to expand the scope of their intramural activities, broaden their extramural activities, and improve their physical space. As the number of such programs grows there is always the danger that innovation will be exhausted and creativity will not be nurtured. Innovation works on a small scale, thus if you want to ensure that

successive programs are progressive in their design it is important to expose staff of newly funded programs to good models, provide consultation and training, and nurture those who express creativity.

Parting Comments

Our experience with these programs has shown us that top-down program development can work, particularly if it encourages innovation and experimentation. The measure of our success can be seen in the \$1.25 million that was appropriated, following the completion of our initial demonstrations, for the development of 25 program sites to serve an additional 300 older adults with developmental disabilities. This appropriation has led to a faster rate of growth in the program.

We tried to promote physical integration as much as possible by encouraging all the programs to chose sites that were not part of a building that housed other programs for persons with developmental disabilities. We were successful in half the cases in the first group and increasingly successful in the second group. We also tried to encourage extramural activities as much as possible (that is, getting off site for trips and activities); we were successful in some settings, not so successful in others.

We have continued to hold cluster meetings for the programs. These included OMRDD and SOFA officials, senior day program staff, and other providers who were interested in joining the expansion. The meetings produced exchanges of information and have led to the formation of a senior day program providers group. What started out as a small scale demonstration in five counties has become a full-fledged program across the state.

Further, this effort has been expanded to include funding for not only additional site specific senior day programs, but also for brokering efforts and individualized retirement opportunities -- thus expanding the options and opportunities available to all seniors.



Rhode Island's Apartment Residence Program

Lucille Nahemow, Ph.D.1

Case Abstract: This case study describes a supportive living apartment initiated by the Rhode Island Division of Retardation and Developmental Disabilities for a group of seniors in a senior housing complex in Providence, Rhode Island. After the state governor made a commitment to close the state's public institution, the Division targeted a group of ten seniors for relocation to a community housing program. It was decided in involve them in community activities as much as possible, using a variety of community amenities and resources. After eleven years, the effort has proved to be productive, showing that the seniors are accepted by the other residents of the complex and involved with a number of community activities.

Introduction

A problem that has plagued most efforts to relocate people with mental retardation into communities is that although they are placed in a community, they do not become of that community. For example, a follow-up study of 1,000 adults discharged from a Connecticut state mental retardation facility (as a result of a class action suit) found that after a year there was almost no evidence of interaction with other members of the community. Certainly, a number of variables can influence such a finding, some related to program design. Still, it is generally believed that living in the community improves quality of life and personal functioning. However, little or no evidence exists that actual social integration occurs.

The top down effort described here is unique in that it was not a demonstration project. The development of a series of supported living apartments was the direct result of the implementation of a specific state policy designed to appreciably change the lives of the older persons involved. It represented a mainstream resolution of a widespread problem for seniors with mental retardation, who, with a long history of institutionalization, have had little or no opportunity to be involved with a natural community.

When seeking housing for people with severe mental retardation, often the first problem encountered is the antagonism of other people in the community. Ironically, additional problems are created by the bureaucratic structures that surround and are often necessary for the mainte-

nance of accountability in a decentralized system. These problems (described by Allen and his colleagues at the 1981 convention of the American Psychological Association) can include:

- conflict and confusion over priorities, which develops when it becomes apparent that those activities which leave a visible trail, like report writing, are more highly rewarded than contact with the consumer;
- diffusion of responsibility, which is typical in a bureaucracy;
- input overload, where direct care staff are accountable to the greatest number of people for the largest number of tasks; and
- tendency to employ negative scanning, where a facility which does not attract bad press is considered a "good" facility.

Thus, when the rules determining accountability are vague, a survival mentality prevails which places pressure on the direct-care staff to avoid innovative practices that have the potential to go awry and cause unwarranted attention. Special demonstration projects are usually necessary because, as a number of the case studies illustrate, they provide an environment with financial and professional supports. Rewards are expected from a source other than the bureaucracy.

This case study describes a supported living arrangement in Rhode Island, run by the Rhode



Correspondence should be addressed to Lucille Nahemow, Ph.D., Professor, University of Connecticut, School of Family Studies, U-38, Room 106, 348 Mansfield Road, Storrs, CT 06269-2058.

Island Division of Retardation and Developmental Disabilities (DORDD), in which there is evidence of stability of staff and genuine community integration. Also explored are the reasons for this success and consideration whether the arrangement is unique or replicable.

Project Description

In the early 1980s, the Rhode Island Division of Retardation and Developmental Disabilities adopted a policy of community services development and followed a gubernatorial commitment to close its public institution, the Dr. Joseph H. Ladd Center in North Kingstown. Among the state initiatives undertaken to implement this policy was the development of a number of supportive apartment units across the state. The initiative resulted in the Stratford House apartments in Providence. Other similar units, also managed by the DORDD, were developed nearby; together they were called "Community North."

In 1981, when the Ladd Center began to relocate persons with mental retardation, a private management company that was in the process of renting senior housing apartments built with HUD Section 202 funds, agreed to a cooperative venture in which a number of residents from the Ladd Center would be integrated into its housing units. Under the federal HUD Section 202 housing program, 10% of the rental units in a housing complex are to be set aside for persons with a disability.

For this particular initiative, all ten persons chosen for the project were over 60 years of age and were either severely or profoundly mentally retarded. All had medical problems in addition to mental retardation. All had lived in the state institution most of their lives; four had been institutionalized since they were seven years of age.

At its inception, the relocation was considered problematic by the staff involved. Not only were they severely retarded, but they were also "old people." There was a general belief, albeit unfounded, that old people were too set in

their ways to accomplish a major change in lifestyle. The relocation was supported by a firm commitment on the part of state DORDD officials and Ladd staff to make the move successful. State DORDD decision makers felt that the similarities between the seniors with a developmental disability and the other tenants with whom they would share a building would assist in their relocation. In their eyes, there were many similarities: the seniors with developmental disabilities were about the same age as the other tenants, they had similar ethnic backgrounds, and they had families who resided locally.

The building complex chosen was in Providence, a city of some 157,000 persons. The supported living arrangement was created by annexing four adjacent apartment units on the ground floor of the building. The apartments each contained a kitchen, living room and one or two bedrooms. They were all somewhat different from one another. The units opened on a wide hallway with access to the backyard.

The DORDD and the state employee unions worked out an agreement whereby the staff employed at the Ladd Center would continue to work with the residents who had moved into the community. An intensive training program was part of the transition from institution to community. The staff assigned to work at the apartment unit were all trained together. Both day and night workers temporarily worked during the 8:00 a.m. to 4:00 p.m. shift. The transition took three months.

As with any new venture, there was much uncertainty. The seniors who were to participate in the project did not know one another; they came from different buildings at the Ladd Center. Their families were contacted in an attempt to make them part of the transition. Staff also were unfamiliar with all of the new residents. In addition, the seniors were often unfamiliar with the new situations encountered at the housing complex and in the surrounding community. One of the original staff members offered some interesting comments; they are shown in the accompanying box.



Some comments from staff

"They had to get used to us. We had to get in our mind that each person was an individual. It was a new concept for some of the staff."

"We would take them out to restaurants to see what their reactions would be. How would they react to spaghetti and meatballs? They were not used to eating food hot. For all those years in Ladd it had been luke warm."

"They did not comprehend the change right away. Some of them took over a year to get used to the apartment. Everyone took habits from Ladd to the apartment. They never knew what it was like not to have everything uniform. At first they were surprised by the different colored towels, because at Ladd all towels were white. Even clothing was a novelty -- they never had their own clothes before."

Toward the end of the transition period, the seniors were brought frequently to their new home. By then they got to know one another pretty well. Only then did they move into the building permanently.

The apartments were originally established as an ICF/MR facility, but were subsequently granted Home and Community Waiver status. Staff was on duty 24 hours-a-day, seven days-a-week. Seven of the 10 original seniors made the transition successfully. The three who had the most difficulty were those who were the most capable, at least according to their measured intelligence. After they returned to the Ladd Center, three other seniors were recruited. These new people all successfully made the transition.

By 1992, six of the original seniors still remained at the residence. One of the residents died, and a new person, admitted when she was 79 years of age, came to the apartments from her family home. Currently, there are six women and four men residing in the apartments. Their average age is 72. They are a diverse

group, both racially and in terms of religious affiliation.

By any standard, these are old people, and they have a variety of health problems. For example, during the first week in January 1992, three of the seniors were hospitalized simultaneously with severe flu or pneumonia. Two of them used walkers, one seemed to be showing early symptoms of Alzheimer's disease, and for several, incontinence was becoming more frequent than it was five years ago.

Health care is managed by the direct care staff with the assistance of a nurse who is on call. With the exception of their dental needs, health care services are obtained through practitioners in the surrounding community. They use local amenities for recreation and shopping. Goods and services are purchased locally. They attend local churches and synagog. These services were a factor in their integration in the community. For example, communion was achieved by three very proud residents.

Socially, the seniors are very active. During the day they all go out to work, recreation centers, and nutrition sites. In the evening, they often go to the seashore to watch the sunset, go shopping, visit parks, and enjoy barbecues at the complex. They have group parties at least once a month to which all family members are invited. They go on several trips a year to other states. Their latest trip was to New York City where they went to Radio City Music Hall and later ate dinner out. Most of the families come to the events to which they are invited. Many take the seniors home for special occasions. They, as well as neighbors and even local tradespeople, save food "cents off" discount coupons for the group. The coupons are used to reduce the food bills, and in this way parties and guest dinners are financed.

Although there was some initial antagonism from other tenants in the building, there is apparently none currently. When we inquired, we found that over half of the other building tenants knew the seniors in the Stratford House apartments by name or had been there to visit. The other elderly tenants consider these people

"good neighbors" for a number of reasons, including "they are clean," "they do their share in the building," "they have a right to be here" and, "they invite me to their parties." One factor that has helped forge ties between the apartment program and the other elderly tenants is the availability of the apartment staff to aid other elderly tenants in the building when health or police emergencies occur.

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Program staff have made it a point to ensure that the identity of the seniors is meshed with that of the greater community. The use of community resources, participation on building committees, use of community amenities -- like neighborhood parks, recreation facilities, and shops -- and involvement with local health care providers provide for those tangible links to the community.

Lessons Learned

State directed ventures can accomplish the ends for which they are intended -- if administrators are aware of problems (potential as well as actual) and become involved in their solutions.

The involvement of senior administrative personnel, in this case the commissioner, is often necessary in top-down ventures. This may be easier to accomplish in a small state like Rhode Island with a tightly knit provider structure. However, state level agreements and interventions often are needed to preclude problems as new initiatives are tried.

It is possible to successfully integrate individuals with mental retardation into community housing without additional funding.

In this case generic Medicaid based funding was used to support the apartments, funding that was generally available. The transition from ICF-MR to Home and Community Waiver funding provided added impetus to run a community-based program. The stable funding scheme provided the basis for the gradual increase in community integration that occurred over many years.

Parting Comments

Despite a great many problems, currently exacerbated by the fiscal crisis in the state, eleven years after the inception of supported community housing for people with severe mental retardation, there is evidence of the program's continuing vitality. Integration of the residents with the community is a hallmark of that vitality. In this case, a top-down state effort to affect policy -- particularly a policy that promotes community integration in housing and other services -- has proved to be both practical and the right thing to do. The seniors with mental retardation who live in the Stratford House apartments have benefitted greatly.

Nevertheless, complacency must be avoided. Although this looks like a success story, that success is unquestionably temporary. One can not solve all problems once and for all. The results are always fragile. Like maintaining democracy, constant vigilance is required.

In looking back on the effort, a number of questions can be raised, including:

- How did this particular apartment residence avoid problems of community rejection and of bureaucratic stagnation?
- To what extent can we expect this demonstration be generalized or repeated?

The community did not reject the supported housing for many reasons:

 An urban environment was selected in which there was great deal of population diversity.
 People moving into the building were of all races, creeds, and of many different ethnic ori-



gins. In this diverse environment persons with a developmental disability were not strikingly odd, and they were similar to others in age and ethnic background.

- People did not own their own homes and therefore were not concerned that their property values would be reduced.
- The seniors with a developmental disability moved in at the same time as the other tenants, before anyone claimed ownership of the building.
- The transition was made with sensitivity to the feelings of the community and the other tenants living in the building. Meetings were held in the community room explaining the move to any interested tenant.

The explanation of how bureaucratic gridlock was avoided is more complex. Rewards for innovation were built into the system by the unlikely combination of the state bureaucracy and the unions. These usually warring units worked in tandem to avoid some of the typical pitfalls of such a system and undertook some remarkable cooperative efforts to make this demonstration a success.

First, an internal support network was developed through inservice training. Supervisors were not merely critical, they also helped with trouble shooting, thus developing mutual respect. A valuable innovation was the maintenance of professional style contact between direct-care staff of different supported living units. From the very beginning, workers were

encouraged to get together, gripe, discuss problems, and share bright ideas, thus reinforcing one another and encouraging the spread of innovative solutions. In this manner, for example, the creative use of supermarket "centsoff" coupons spread from one unit to another.

- Second, there was remarkable continuity of staffing. In a system which typically has a high rate of turnover, not only this particular apartment unit but others as well, maintained the same staff for long periods of time.
- Third, and possibly most important, there were both continuity and support from above in times of crisis. Unlike a typical bureaucracy, the administration tended to support the direct care staff unless convinced they were at fault. The commissioner of the division prided himself in his strong connection with the communities. He would personally meet with an enraged group of citizens to help sort out any problems when they arose.

Thus, the system developed two unusual features: flexibility and a modicum of common sense. It should be noted that within the Rhode Island system, the apartment residence project described was not unique, but simply one of many. This indicates that the model can be replicated. We can only speculate about the degree to which the model developed can be applied elsewhere. Clearly additional research is needed to find out which elements were essential and what combinations were required to be present to produce the desired effect.



irement Assistance Ventures

The most typical approach to retirement is that which occurs naturally, evolves as part of one's life tasks, and promotes the living of an ordinary life. In many instances, persons with a developmental disability will be able to define their own needs for involvement and participation in their community's senior services, leisure time use, and other avocational activities. Such natural approaches can be facilitated within these situations just as they can be for other older persons without lifelong disabilities. People need to know their options, how to access them, and then how to behave once in them.

Many models exist that draw upon specially preparing, mentoring, or aiding older persons with retiring successfully. The examples chosen for inclusion in this section draw from a variety of experiences of facilitative retirement. They all, however, have one thing in common: they aid -- by example or by direction -- older persons with a developmental disability to use common aging network resources within their community by pairing that older person with a friend or "coach." Such coaching or facilitation models have produced many sound lessons; for example, retirement, like all life tasks, requires a period of preparation and emotional adjustment; the abilities to do things associated with retirement can often be taught best by modelling; you can never anticipate all the things that may impede your efforts to aid a person in adapting to retirement; retirement often works best when experiences draw from a potpourri of situations; each older person will adapt at his/her own pace (do not expect that everyone will adapt equally well); and preparing aging network personnel to work with older persons with lifelong disabilities will facilitate the access and adaptation process.

The lessons learned? Helping someone adapt to new situations can work better than expecting that person to know how to use that situation naturally. Planning the means to social bonding and orienting to one's community can aid in successful aging. Role models can be family members, friends, volunteers, or even paid companions -- all have a valuable contribution to teaching retirement skills. Facilitative retirement depends upon two things: people retiring when they are ready and wish to and the expansion of options and choices that make retirement an enjoyable experience and an integral part of normal life.

Step Forward Retirement Coaching

Sally Cheseldine¹

Case Abstract: This case study in Oldham, England describes a retirement preparation project that helped a number of seniors become oriented to retirement options. The project, undertaken in three different group experiences, used guest speakers, group instruction, and guided exposure to community options and amenities. The participants were pensioners who were interested in learning more about their community and the activity options available to them. It was found that the group members became more familiar with their community options and continued to meet regularly with one another after the formal support group meetings stopped.

Introduction

Services for children and young people with a mental handicap appear to be relatively well-developed and coordinated. Attention is now turning towards the needs of older adults. Older people with a mental handicap rarely have been allowed to plan in advance for their later years. In some areas of the United Kingdom there has been pressure on them to "retire" from training centers to enable a "through-put" of younger people, while in others, attenders may continue for as long as they wish.

Because we felt that older persons needed to become competent in assessing options for later age, we created a series of support groups that would help in retirement planning. Our ultimate aim was to help older people with a mental handicap establish contacts in the community with other people of their own age. This monograph describes our effort in setting up and maintaining such retirement support groups. The project took place between 1985 and 1987.

Project Description

In 1985, we set up a group to examine the needs of older people with a mental handicap in the town of Oldham, England (a community in the greater Manchester area). It was made up of members of the Oldham Community Mental Handicap Team (CMHT), officers-in-charge of two social services residential establishments,

and the director of Age Concern Metropolitan Oldham (ACMO).

First, we worked to identify older persons who might be interested in the support group program. The town's register of persons with a mental handicap indicated that 178 of the people listed were 40 years of age or older. This older group made up one third of the total of the overall register group (N=538). However, we knew that there were other people in this age group who had not yet come to the attention of the CMHT. Only 43 of the 178 people identified were living in staffed residential establishments within the Borough of Oldham, although another 25 were in similar settings or hospitals outside the area. These individuals were included in our counts because it was envisioned that most of them would return to the town. The remaining 90 people were living in ordinary housing in the community. At least 16 were living independently, either on their own or with a friend. The others were living with relatives, such as brothers and sisters, nephews and nieces, or very elderly parents. We assumed, therefore, that in the not too distant future there would be approximately 90 older people with a mental handicap requiring support from Oldham Mental Handicap Services.

Next, we began to organize our ideas on how to set up the support groups. Instead of referring to these support groups as "pre-retirement groups," which was thought to have connotations of "slowing down" or preparing for an empty life style, it was decided to call the



Correspondence should be addressed to Sally Cheseldine, Ph.D., 3 Ravelrig Hill, Balerno, Edinburgh, Scotland EH14 7DJ. Dr. Cheseldine is with the Forth Valley Health Board/Mental Health Services of the Royal Scotlish National Hospital (Old Denny Road, Larbent FK5 4SD Scotland). A more detailed description of this project is published in *Journal of the British Institute of Mental Handicap*, 1989, 17, 96-100.

groups "Step Forward;" hopefully conveying a more positive image and approach. Initially, we conceived of the support groups as operating along the lines of the pre-retirement groups operated by our town's adult services agency. These groups would involve lectures and discussions. However, as will be explained later, we modified our approach over the three groups.

Over a two-and-a-half year period, three Step Forward groups were organized, each differed from the other in some way. Although valuable lessons were learned from these variations, it became clear that a perfect "package" had not been found. A problem inherent in all service "packages" is that service users are required to fit the package, rather than the service adapting for their individual needs. It is our hope that the following description of the three support group courses will provide ideas for other practitioners and stimulate discussion about the development of such services in the future. The Support Group 1 course is described in more detail than the others, as it was the foundation of the subsequent groups.

Support Group 1: Our Experiences and Lessons Learned

Age Concern Metropolitan Oldham (ACMO) runs pre-retirement sessions for several types of groups, for example, for staff working within the National Health Service. Although these sessions provided us with useful topic headings, it was felt that the content of the sessions would need to be adapted for people with a mental handicap to take into account their individual circumstances and needs. Eight topics were selected and were incorporated into a series of sessions that ran for 13 weeks. Safety, cooking, money management, leisure and benefits were covered in two sessions each. Health, voluntary organizations, and housing were allocated one session each. The invited speakers had particular knowledge or interest in specific topics. For example, a health worker talked about "Health/ Looking After Yourself," and the head of a further education center dealt with "Leisure" and "Visits to Community Centers."

The course was held weekly in a local terraced house. Other than those who were scheduled to speak, the only staff member to attend was a representative from ACMO. Eight older people with a mental handicap known to the CMHT were part of the group. They were invited to participate based upon three criteria: 1.) their perceived need, 2.) if they had little to do during the day, and/or 3.) if they had limited social contacts. Each participant had an opportunity to meet the speakers during a special coffee hour four weeks prior to the beginning of the course.

Eight people attended the first session. One person subsequently dropped out because he disliked another member of the group. Another only attended three sessions, because his interests were served better by an ordinary preretirement group. The remaining six people attended all of the sessions unless prevented by illness.

The speakers reported that everyone participated enthusiastically in discussions, as if they were trying to make up for lost opportunities to express their feelings on the various topics -- so much so, that the speakers had to learn how to interrupt more appropriately. Audio-visual aids, such as slides and posters, seemed useful to focus attention on the topics and speakers took care not to convey too much information in one session.

From this initial experience, we felt that the same topics should be covered in future courses, but the composition of the group could be varied. We questioned whether it would be better to have groups of people who were already living in the community and, therefore, had much in common, or mixed groups who could learn from the wider range of each other's experiences. We decided that mixed groups would be more beneficial.

Before and after course interviews were conducted. In these interviews we looked at specific items of information that were taught in the course. We also used a weekly diary and a questionnaire to assess the effects of the course on day-to-day events in group members' lives.



As the group members had been selected because of their apparent social isolation and lack of structured leisure time, it seemed reasonable to focus on this aspect.

The individual effects perhaps tell their own tale. It seems safe to say that, on average, group members went out at least once a day. It was seen from the diaries that typical activities included taking the dog out, going to shops or for a walk, or going to meet a friend.

A less positive picture was seen in overall socialization. We could not say that everyone had a visitor, even once a week. Admittedly, the issue is clouded somewhat by three members who lived in a residential hostel, thus having permanent "visitors" in the shape of hostel staff or co-residents. Nevertheless, there seemed to have been only a one-way link with the "outside world" for most group members. We also noted that the specific interventions aimed at widening their social contacts were not being undertaken. In retrospect, we would have been naive to expect such a change simply on the basis of 13 widely differing meetings. It seemed that a more structured approach would be required.

After we had a chance to assess the effects of the formal course, we agreed that the group should continue to meet, but on a bi-weekly basis due to the likely effect of the upcoming winter weather, the inability of CMHT and ACMO staff to commit themselves on a weekly basis, and a recognized need to start fading out support (as intensive contact with group members could not be maintained beyond the summer months).

It was suggested that a "life histories" exercise might help the development of individual and group communication. This exercise was given initial impetus by taking photographs of everyone at a Christmas party. Group members were asked to bring with them any other photographs of themselves that they had. Only one person had a photograph taken within the past five years, reinforcing the possibility that, for many people with a mental handicap, their past is either lost or seemingly non-existent. We

sensed that their memories tended to be tinged with bitterness over wasted years.

How different this was from the popular conception of older members of society spending their days steeped in pleasant nostalgia. CMHT workers obviously needed to help people with mental handicaps of all ages to keep a positive record of the good times in their lives.

The idea of trying to work on "life histories" had seemed a good one, but the matter was decided by the group members themselves. Their reactions, on seeing one another after the Christmas break, emphasized their need for such meetings as purely social get-togethers, that is, the chance to chat over a cup of coffee. Their plan for future sessions was followed, so biweekly sessions over the next four months included activities such as gardening, pet care, knitting, and a trip to a local village pub for lunch. In this phase, all the participants found their niche; for example, through gardening knowledge, organizing the coffee, or collecting bus timetables. Obviously, although some structure is important, it is possible to inhibit individual initiatives through over-planning.

After four months, a further attempt was made to reduce support. One group member offered his apartment as a meeting venue, and we suggested that on alternate meeting dates the group would meet there (without the staff). However, the female members said they felt uncomfortable without a staff presence, so the group gradually fizzled out.

Lessons Learned

Experience taught us that there is a need for social skills to be taught in a more formal manner and for more structured introductions to be offered to local facilities.

Upon review, we felt that the breadth of activities had changed for each of the individuals. One woman had started to participate in more activities centered at her residence. One man has become a volunteer to others, visiting them when they were ill. The three men living at



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the hostel continued to meet at the apartment of one of the members. However, the one woman who lived on her own showed the least change.

Support Group 2: Our Experiences and Lessons Learned

The staff who had been involved with Support Group 1 felt that it was a combination of a lack of a staff "leader" and the lack of neutral territory for a meeting place which led to the group's eventual demise. However, taking these factors into account, and primarily because group members reported having enjoyed the meetings, it was decided to repeat the course for a second group. Consequently, eight additional participants were located by referral from workers and other staff in day and residential services.

Six of the second group lived in Social Service residential hostels, one lived in a "wardencontrolled" (i.e., house manager) accommodation, and one lived in a staffed house. As before, the meetings were held in a local house owned by the Health Authority, and followed the format of the ACMO pre-retirement course adapted for people with a mental handicap.

This second group became quite different from Support Group 1. One thing was that its regular membership dropped from eight to three. In retrospect, this was attributable to the following factors.

- » The deregulation of the public bus system that occurred at the time of the group's formation led to a certain amount of confusion concerning schedules and routes, not just for people with a mental handicap but for the population in general. This confusion reinforced the need for workers to support these individuals in their use of public transportation, in order to enable them to attend the meeting. At least two group members were affected by this.
- » The staff who organized the Step Forward sessions felt that, on occasions, their efforts

were not taken seriously by other staff, in that other workers arranged for the group members to attend alternative functions that supposedly were seen as more "worthwhile" because they were more costly.

In addition to the Support Group 1 course, excellent support had been given by ACMO, but due to managerial decisions, this support became less consistent and reliable for Support Group 2. Staff members, were unable to attend every session; thus, there followed a lack of leadership for the group. In addition, the range of abilities and opportunities available to group members was so wide that topics such as money management and types of housing were of limited value.

In view of the poor attendance, we decided not to extend the group meetings after the thirteenth session, other than to arrange a pub meal for the three "die-hards." Some value was salvaged from the experience, however, in that it prevented the work group members from "sitting back on their laurels" thinking that they had found the ideal formula. Before embarking on any further meetings it was clear that a great deal of careful planning was required before we could proceed in organizing another such group.

We wrestled with a number of ideas. One was that perhaps more general topics were needed. A particular comment from one speaker is worth noting: that while the staff were very interested in the trip to a community center, there was no follow-up by the older group members. We question for whose benefit was the trip made.

Lessons Learned

Sometimes you can not anticipate all the barriers you may encounter in attempting to help someone learn how to retire.

We could not have anticipated that an outside factor, such as the bus system becoming dysfunctional would cause confusion and disruption to our training efforts. Nor could we have anticipated the problems posed when our



efforts were not taken seriously by other staff who were involved in non-related domains of the seniors' lives. Nor could we have anticipated that factors internal to agencies participating in the project (such as changes among the managers) would have caused such major disruptions to our efforts.

Support Group 3: Our Experiences and Lessons Learned

Undeterred, the work group met again. By this time the ACMO had a new director who was keen on committing the organization to continued involvement. The director provided Manpower Services Commission (MSC) workers as "link-people" for the meetings. Therefore, we decided to run a third group during the summer months, and to involve the group members much more in the content of the meetings. We also decided to place more emphasis on why they had been invited to participate, explaining that they were getting older and encouraging them to look for age-appropriate services. This was, after all, the ultimate aim -- to help people establish contacts in the community with other people of their own age.

We requested names of possible attenders and seven were put forward. Three lived in a residential hostel, two lived in warden-controlled accommodation, one lived independently, and one lived with his sister and brother-in-law. As these people were accepted, we emphasized to "key workers" that the onus would be on them to ensure that the group members would attend.

In March, an informal get-together was held to establish areas of interest for the members of Support Group 3. ACMO and CMHT staff attended, using posters and various assorted objects (such as cameras and equipment borrowed from a local interest center), to encourage people to talk about their existing interests or those they would like to develop. Several ideas were put forward: history, "Oldham as it was," royalty, cake icing, household plants, and day trips.

A schedule for the 13 meetings was drawn up, incorporating these ideas with some of the

original topics from previous courses. We felt that some of the original topics could be retained, namely, "Looking After Yourself," "Basic Cooking," and "Pets." There were also sessions conducted entirely by the ACMO -- "Celebrating Age" and a trip out -- and an introductory session called "Getting to Know Each Other" for which group members were encouraged to bring photographs of themselves, their families, pets, houses, and so forth. It is worth noting that, yet again, very few had any photographs that were less than five years old. In effect, they had no photographic record of their life.

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Prior to the official start of the group the ACMO requested some basic staff training in mental handicap for the MSC workers. A clinical psychologist and an officer-in-charge of a residential hostel, who has a son with a severe learning difficulty provided this training. The session, lasting one-and-a-half hours, covered the wide range of abilities that exist in mental handicap, the concept of structured learning. community living, normalization and values, and age-appropriate activities. Although this sounds like a great deal to cover in a short time, we felt it was necessary to touch on all these aspects in order to promote a positive attitude. Although none of the ACMO workers who participated in this staff training subsequently took part in any of the Step Forward sessions, one of the MSC funded workers did attend most sessions and established a very good rapport with group members. It does seem important to have a



consistent "link-worker" who is willing and able to sustain this rapport.

A good level of attendance was maintained by Support Group 3 members throughout the course; the only absences resulted from illness. A certain amount of prompting by key workers may have contributed to such few absences.

There was a break of one month at the end of the 13 sessions, followed by an afternoon coffee session when, in addition to planting bulbs ready for the spring, course members were asked to consider how they wished the group to proceed. No ideas were put forward, so the work group decided to organize a reunion with the regular attenders from all three groups. At this point, Step Forward could be seen as moving into a distinct second phase.

Lessons Learned

It's useful to have a plan for teaching the necessary skills necessary to enjoy the activities associated with retirement.

We found from an overall review of all our attempts that:

- sometimes to get a point across audio-visual aids are vital;
- it may be useful to organize a group activity, such as bingo, to act as a "warm-up" prior to the more serious business of the day; and
- for sessions such as "Getting to Know Each Other," a better worker-to-senior ratio is useful to facilitate more interaction.

Parting Comments

As noted, we decided to hold a reunion of all the Support Group members. The reunion was attended by 15 of the members. The obvious pleasure that each of the participants showed when meeting their friends again seemed to make the whole effort very worthwhile.

During the latter phase, another organization became involved -- The Oldham Leisure Group -- whose aim is to match volunteers to adults with a mental handicap within the context of "normal" leisure activities, and who volunteered to take over some of the work with the members. The Oldham Leisure Group was particularly keen on developing links with local community centers. The Leisure Volunteer Coordinator had already established links with a community center in Oldham and, after attending some Step Forward meetings, helped to set up a Friendship Circle there. This group met monthly and was open to any members of the Step Forward groups, volunteers from the Leisure Group, and other members of the community center who could "drop in."

The Step Forward group members joined the community center, paying a membership fee of £2.00 (about US\$3.40) for the year. At each meeting there were opportunities to chat with friends and to participate in various activities such as bingo, darts, dominoes, cards, and other activities. One of the volunteers had offered to take over the long-term running of the Circle, so it moved at least one step further away from the paid service providers. He became the liaison with the Volunteer Coordinator and the Step Forward work group.

We decided to run another series of Step Forward groups and continue the series. In this way "new blood" continued to be channelled into the Friendship Circle, and the goal of helping older people with mental handicaps to have a more positive approach and to maintain and develop more social contacts was met.

Although Step Forward made some progress in meeting the needs of older people with mental handicaps, there is still a long way to go. Some practical steps had been identified that others may like to follow -- such as helping people to reminisce over happy memories, establishing links with Age Concern, or like organizations, and encouraging the maintenance of existing friendships. But it is important to recognize that these goals will not all be easy to accomplish.



If people are to overcome the "double jeopardy" of having a mental handicap and becoming old, a strong commitment will be required from everyone involved.

SLARC Retirement Coaching

Allene M. Jackson¹

Case Abstract: This case study describes the experience of the St. Louis ARC in setting up a retirement coaching program. The program was designed to help seniors with developmental disabilities become more adept at accessing generic senior programs in their neighborhood. Much attention was paid to preparing the seniors and the various agencies to activities which the seniors would find worthwhile and to the seniors' families. It was found that the coaches were successful at helping the seniors with developmental disabilities to be integrated and that funding sources were available to help with this process.

Introduction

The retirement coach is a tool for community integration of older adults with developmental disabilities into the aging network. As individuals with developmental disabilities age, programming must change focus from vocational training and employment to retirement preparation and implementation. If true community integration is to take place, seniors should:

- be included in existing aging programs such as senior centers, AARP, senior citizens groups, day care and other community activities;
- not be segregated by developing or expanding programs for them in the developmental disability network; and
- be encouraged to act as volunteers, as many seniors are, and be given the opportunity and status of contributing their time and talents to the community.

The retirement coach is an extension of the job coach model and offers seniors with a developmental disability the training and support

to participate with their fellow seniors, who do not have a developmental disability. The program's goal is to help the senior to attain as much independent participation as the senior can achieve, with the retirement coach phasing out support to fit the seniors' needs. However, the retirement coach should continue to be available to the senior program site, in the event a problem arises. This availability of staff support may encourage senior programs to welcome our seniors into their activities. Staff can also be used to assist in the senior program as well and both staff and seniors can be seen making positive contributions to the community.

The St. Louis Association for Retarded Citizens (SLARC) is a non-profit organization serving individuals of all ages with developmental disabilities, through its Leisure, Residential Respite, Early Childhood, Adult Day, Aging, Employment and Family Support Programs, in the metropolitan St. Louis, Missouri area. It developed the Transition to Retirement Program some years ago; it is now functioning at the SLARC's Sunnen and Gibson Centers in St. Louis. Seniors at these sites come from their own home, group homes, nursing homes and a state-operated habilitation



Correspondence should be addressed to: Allene M. Jackson, ACSW, Program Coordinator, Aging Services, St. Louis Association for Retarded Citizens, 1816 Lackland Hill Parkway, St. Louis, MO 63146.

center. The majority of these seniors' parents are deceased and there is minimal contact with other family members.

The philosophy of the Transition to Retirement Program is to allow seniors to participate in retirement activities, increase the individuals' level of independence and provide opportunities for integration into the community. Program activities include communication, socialization, exercise and arts and crafts. Individuals are also provided with opportunities to improve their decision making skills.

This last component is very important, because many individuals -- especially those coming from an institutional setting -- have been given little opportunity to learn how to react to choices. In closed settings, residents are generally taught and rewarded for being compliant and once in the community must learn that they can indeed choose what activities they want to participate in, where they would like to go, and who they would like for a friend.

Project Description

The Retirement Coach Program began because, although community integration is a goal of our Transition to Retirement program, activities were usually undertaken in a group with little individual choice. Although many seniors go out into the community in large groups, many go alone, as a couple or in small groups of two or three and our seniors should have the same opportunity. More one-on-one staff support was also needed for a greater variety of community retirement activity.

The first retirement coach was hired April 1990 through a private grant. The second retirement coach was hired July 1990 through a grant from the Productive Living Board (PLB; a Missouri Senate Bill 40 Board). Funding from the private grant was not renewed, but the Productive Living Board agreed to fund the Program for the 1991 - 1992 fiscal year. They indicated, however, that because of a memorandum of agreement between the PLB and the

Regional Center, future funding should come from a Purchase of Service contract (POS) from the Regional Center.

The retirement coaches integrated seniors from the Transition to Retirement Program at our Sunnen and Gibson Centers into various community and volunteer activities. The activities included participation at senior centers (including going on day trips with the other seniors), an AARP Group, various cultural and community activities, a Happy Hour (with non-alcoholic beer), the horse races, fishing at a local park, and going on a date. Seniors volunteered at a Children's Day Care Center, a local church where they stuffed sleeping bags for the homeless and helped with mailings at the Alzheimer Association, Dance St. Louis and the American Heart Association.

Continuity of volunteering at the same site is important in developing relationships with other volunteers and the agency staff. Also being available when volunteer help is needed builds up credibility and reliance on senior help. Our volunteers had the same status as all volunteers and were included in volunteer recognition events.

To help us keep track of program activities and the work of the retirement coaches, we devised a number of data collection forms and other mechanisms. For example, retirement coach activity data were collected on a monthly basis in the following areas:

- senior preparation for integration
- · community integration of the senior
- senior follow along
- site development
- travel time
- documentation
- meetings
- · staff development

Senior activity data were collected monthly on an activity form that identifies the following:

- time spent and training needed in preparation for integration
- community integration activity



- · hours spent in the activity
- staff/participant ratio
- IHP goals/objectives activity addresses

Our staff activity form is in the process of revision to facilitate its use in other community integration situations. Data collected from all community integrative activity are being used to determine a rate for a POS from the Regional Center, so that separate rates for each community integration activity do not have to be established.

We feel it is important to relate the retirement activities to Individual Habilitation Program (IHP) goals and objectives. Aging individuals may not have the energy level that younger individuals have and may need time to rest or be involved in quieter activities. Thus we ensure that age-appropriate activities and functions are part of each senior's IHP.

The retirement coach may involve family members as well as the senior in planning for the future. A family planning tool and a retirement planning tool are being developed to provide further assistance with the process. Families may be referred to the ARC FamLinks Program, which offers a support group for families with offspring who have a developmental disability.

Developing staff now and in the future that have knowledge about aging individuals with developmental disabilities and their families was important to our agency's overall goals. We felt that agency staff development in this area should be done on a continuous basis. In addition to continually training our staff, we have encouraged practicum students and interns to spend time at our agency. Because the greater St. Louis area (a population in excess of half a million people) has a number of fine universities and colleges, we generally were able to recruit students from a variety of fields, including education, sociology, gerontology, social work and psychology.

A paid practicum was offered at the St. Louis ARC, with the support of the PLB, and we were able to offer three social work students pract-

icum placements. Not only did they gain knowledge about this population, but gleaned valuable information about the agencies which serve it and the networking that is necessary between the fields of aging and developmental disabilities. Perhaps, more importantly for us, they also provided assistance to the retirement coaches in helping them take physically impaired individuals into the community and thus expanded the number of individuals we could get to go out into the community.

Lessons Learned

Look to multiple funding sources and use of practicum students.

SLARC secured funding from both a private foundation and the Productive Living Board to pilot the program. It was hoped that the program could be expanded to serve individuals not only in the Transition to Retirement Program, but from their community place of residence as well. This funding unfortunately was not available, but practicum students can be used for this program. Long-term funding is being sought from the State Department of Mental Health.

Seniors should contribute to the senior program in which they participate.

Our seniors should pay whatever fees other seniors pay for meals, activities or transportation costs. They should also be encouraged to volunteer their time as do other seniors. Our seniors deliver meals-on-wheels from senior centers and take their turn in clean up duty after meals.

Cultivate" the directors of the senior center or senior program the senior wishes to attend.

The directors of senior centers or senior programs are usually busy people and do not like surprises. Talk with them about your seniors and what they can contribute to the program. Give the director your name and phone number to call in case of an emergency or problem situation and be sure to check back regularly.

Choose your retirement coaches carefully.

Choose retirement coaches that have good social skills with and enjoy being around all seniors. One of our retirement coaches is a senior herself and looks right at home in the senior center. The other, however, is in her twenties but enjoys working with seniors and they enjoy her participation and program ideas.

Parting Comments

The Retirement Coach Program has been a

success due to the enthusiasm and social skills of the seniors that have participated; the innovative ideas and cultivation of sites by the staff; and the openness of senior directors and other senior participants to include our seniors in their activities.

When other seniors see that our seniors can be capable and contributing members of the group, they begin to see them as peers. And when they see them as peers they see them as people first and accept them as such.

Mississippi Retirement Skills Teaching Program

Carl S. Laughlin, Paul D. Cotten and John W. Simpson¹

Case Abstract: This case study describes a project which took place in a rural area of Mississippi that consisted of helping a group of seniors with developmental disabilities learn retirement skills. One component, held in a classroom setting, taught participants fundamental skills and behaviors to help them with social integration. The second program involved the participants in a series of community activities. The program set up a training curriculum and on-site experiences within the area's senior centers. All f the seniors participated successfully in generic senior programs with other service recipients. They wer: able to use the skills they gained by participating in this project in order to feel more comfortable with participating in various community activities.

Introduction

In the early 1970s, administrators working within Mississippi's mental retardation and mental health system expressed concerns regarding the lack of appropriate services available to elderly individuals with mental retardation who were living in rural areas of the state. These concerns prompted us to compare the functional abilities of elderly persons with mental retardation who were residing in ICF/MR with their age peers who did not have mental retardation and resided in general ICFs.

One finding was that many seniors with mental retardation were interested in retiring to something other than a structured programmatic regime and wanted to make their own choices as to how they could spend their time. These findings led us to consider a number of questions about the services that were available to seniors:

- What were the seniors' programmatic needs?
- What were the most appropriate settings in which to meet such needs?
- Which function of state government should assume the primary responsibility for developing a service system for individuals who qualified for services which were provided by



Correspondence should be addressed to Carl S. Laughlin, M.S., Paul D. Cotten, Ph.D. or John W. Simpson, M.S.W., Boswell Retardation Center, P.O. Box 128, Sanatorium, MS 39112.

both the elderly and the mental retardation service networks?

- How could such a service system be developed and implemented within a rural setting?
- Did these individuals have the right to retire from programming and, if so, to what could they retire?

Our response was to initiate a special effort that involved cross-training of staff in our locality and setting up a two staged pre-retirement and retirement skills development program.

Some Background

Boswell Center, located in Sanatorium, Mississippi, was set up in 1976 by the Mississippi legislature to be one of five service areas for persons with mental retardation operating under the auspices of the Bureau of Mental Retardation within the Mississippi Department of Mental Health. Its purpose was to provide adults with mental retardation with training and practical experiences prior to transitioning to living in a community residential setting. Boswell Center, occupying the grounds of what was previously a sanatorium for persons with tuberculosis, is located in Simpson County (a rural area of some 24,000 persons).

A number of factors aided us in pursuing our goal to provide varied and integrated community services for the seniors served through Boswell. Certainly, the most important factor was a series of recommendations in the State Plan for Services for the Elderly Handicapped Mississippian. This plan identified a suggested array of services, such as alternative living arrangements and day services that would be capable of meeting the needs of Mississippi's seniors with mental retardation and other developmental disabilities.

Based upon the recommendations within the plan we requested funds from the Bureau of Mental Retardation to implement a pilot project that would enable us to integrate, both physically and socially, the older adults residing in the

personal care homes spread over the county into senior centers. We targeted senior centers in Simpson County, as well as in Hattiesburg and Jackson -- two cities near to the Center. Using a similar approach to that used successfully by supported employment programs, we were able to place a facilitator with an older adult to ensure that the adults not only developed appropriate skills but were also using those skills to develop interdependent relationships with other seniors using the Center.

In addition to the senior center resources, we targeted other generic senior services such as the local Retired Senior Volunteer Program, the area's transportation services (provided to elderly and handicapped persons), and those services provided to older persons through local churches, libraries, and other civic resources.

As part of our effort, we also developed a number of senior group (or retirement) homes. After we began the operation of the first retirement home, however, we quickly realized the importance of preparing the home's seniors for retirement. Thus, we began the development of the Pre-retirement Training Program where the emphasis was placed upon teaching how to choose from the available options for retirement activities, including where to live, involvement in both paid and non-paid volunteer work, and leisure activities.

As we began our efforts, we understood that while we made some progress toward including older adults with mental retardation within the generally available community services, several concerns or potential barriers were still very much with us. For example, we knew that how these individuals would fare depended, in part, upon how the service delivery system would cope with the attitudes of its general constituents.

Our ability to address these concerns was related to the degree to which elderly individuals with developmental disabilities could be integrated into generic services. We were concerned that although we could achieve "integration," it might only be physical integration and not the more crucial social integration. Social



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integration, we reasoned, went beyond a person's mere attendance in a community senior program and really spoke to active participation in activities that included quality interaction with other participants, and thus, represented the assimilation of the person with a disability.

If older adults with developmental disabilities are to be received warmly by the other participants in generic aging programs, such as nutrition centers, senior citizen programs, and day care facilities, they need to demonstrate the ability to function appropriately and have things in common with the other participants.

We reasoned that the best way to facilitate the required learning, while achieving integration, was for individuals with developmental disabilities to begin participating in the senior programs, while at the same time receiving training in the skills they needed.

Project Description

The retirement skills teaching project, described here, used aspects both of the supportive employment model and of the senior volunteer program model (such as the ACTION agency's Senior Companion Program) to promote the integration of aging persons with developmental disabilities within generic services. The project involved two facets: the Community Transition Program and the Supported Psycho-Social Integration Program.

Community Transition Program

The Community Transition Program, conducted concurrently with actual involvement in community programs, was a preparatory program conducted within a classroom through which participants were taught those fundamental skills and behaviors that are needed to ease social integration into community programs. The first phase of the program was comprised of four concurrent segments.

First, classroom training where participants engage in various types of social skills training.

- Second, activities that aid in differentiating between questions and statements and focusing on the specific use for each.
- Third, following participants understanding of the skills noted above, training in more complex aspects of social interaction, such as ordering from a menu, social introductions, and general conversational skills.
- Fourth, discussions of such topics as dining skills, social manners, rules and regulations, money management, and problem solving to broaden generalizability.

The next phase, offering "on-the-job" training, consisted of on-site implementation activities. This segment was crucial to meeting the goal of the program. These activities were designed to relate directly to and reinforce specific program areas of learning.

"If older adults with developmental disabilities were to be received warmly by the other participants in generic aging programs, such as nutrition centers, senior citizen programs, and day care facilities, they needed to demonstrate the ability to function appropriately and have things in common with the other participants."

Activities ranged from simple role playing scenes between the facilitator and the participant, to community trips which help accustom each participant to settings in the community. Each role playing exercise was videotaped, reviewed by the class, and analyzed in terms of the skills being taught. Aside from the obvious benefits of feedback and reinforcement, videotaping added a dimension of fun and excitement that was not necessarily a feature of other training sessions.



The final phase of each transitional session consisted of a skill evaluation segment. This feedback process served as a positive reinforcer and an opportunity for the facilitator to make supportive suggestions about areas that needed additional practice. Additionally, this exchange served to strengthen the sense of trust between the participant and the facilitator, thus creating a positive learning relationship. Equally important throughout the evaluation period was the focus aimed at enhancing the participant's self-respect, and self-worth.

Group counseling was available in addition to the three training phases of the Community Transition Program. The group counseling was designed to help participants understand the relationship between appropriate behavior expected in community settings and social acceptance. The counseling sessions involved a discussion of various aspects of community participation, followed by review and feedback to clarify details that the participant had not previously understood.

Supported Psycho-Social Integration Program

The Supported Psycho-Social Integration Program consisted of involving the participant in community activities with on-going support and providing the opportunity for practice and social validation of the skills which he/she learned. This program, operating concurrently with the training provided through the Community Transition Program, provided opportunities for the participant to take part in various community programs and activities and to receive additional training in conjunction with that activity. Activities included participation in the Retired Senior Volunteer Program, the local Nutrition Center, and other day activities that were provided under the local area agency on aging.

Using the supported employment model as a basis, the case manager conducted an assessment of skills exhibited by general service users at the program sites. The assessment was performed to identify specific skills that may be problematic for a senior with a cognitive disability. Once this assessment was completed, the case manager and other staff involved in the project (e.g.

home managers) focussed on identified skill areas that required additional training. Similar to using a job coach under the supported employment model, seniors participating in this program were provided with unobtrusive training and on-going monitoring at the senior program. As a result of this support, participants could overcome behaviors that, historically, had been perceived as insurmountable obstacles to social acceptance by their age peers.

While the inclusion and acceptance of seniors with a developmental disability by age peers in generic senior programs was one of our goals, it did not constitute full participation indicative of true psycho-social integration. Our other goal, certainly less malleable, albeit much more indicative of true acceptance, was the development of friendships and feelings of interdependence with other service recipients.

"Similar to using a job coach under the supported employment model, seniors participating in this program were provided with unobtrusive training and on-going monitoring at the senior program."

Following the completion of on-site training within the senior programs, peer counselors (other seniors using the centers) were involved in helping the individual make the complete transition to full program participation. These peer counselors served two very important functions during daily program participation:

 First, they conducted on-site monitoring of the seniors' skills in participating. When the senior began to experience difficulties, the peer counselor was supposed to intervene and aid with the problem, thus helping along long-term participation. If necessary, the counselor also provided additional training without interrupting the individual's involve-



Mr. Elliott S.

Mr. Elliott S. is a 63 year old man who had been institutionalized for the past thirty-eight years. During one brief sojourn to the community, Mr. S. exhibited significant problem behaviors and, consequently, was readmitted to the institution.

Three years ago, Mr. S. moved to one of the retirement homes operated under the auspices of the Boswell Retardation Center's Community Services Department. Soon thereafter, he became involved in a project that was integrating aging individuals with developmental disabilities into community programs.

As a result, Mr. S. developed more adaptive interpersonal skills while participating in a variety of aging programs offered in the geographical area. In addition, he regularly volunteered at a local school for children with disabilities. A "coach" helped Mr. S. to develop the necessary skills to facilitate his transition toward successful integration. After the coach withdrew from active involvement, the peer friendships Mr. S. established during the training were maintained and continued. We observed them to be genuine, mutually beneficial friendships.

Given the tremendous success that Mr. S. has achieved thus far, it was expected that he will continue to develop as a contributing member of the local community.

ment in the program.

 Second, the peer counselor and the participant generally realized a mutual benefit to the relationship which ultimately became a real friendship.

The seniors, if they were to be fully accepted by their non-disabled peers, must have been perceived not only as service recipients, but contributors to the community as well. Opportunities for participants to be involved in relationships where interdependence exists abound in community programs. Volunteering is one vehicle that can be used to help cultivate these

positive relationships. By volunteering, individuals with developmental disabilities can provide a needed service and, at the same time, develop lifelong friendships with others within their community. The dependency of others on these volunteers also enhances the volunteers' perception of their own competence and demonstrates the value of the person to the community as a whole.

It became apparent to us that being included in the programs and services of the community's aging network was important for the seniors with developmental disabilities in our catchment area. It also became apparent that to make this inclusion work, we needed a creative, coordinated effort between the aging and mental retardation networks. These networks must combine their efforts, not only in the provision of services, but also in facilitating the total involvement of the individuals with disabilities in order to enhance the likelihood of long-term participation. Psycho-social integration is, therefore, crucial to maintaining this collaborative endeavor.

The accompanying vignette of Mr. Elliott S. illustrates the benefits of participating in the project for one individual with a lifelong disability.

Lessons Learned

Having a state plan that supports your efforts is immensely helpful.

The presence of a state planning document helped set the stage for our efforts. Among the most valuable aspects of this plan was the call for the development of linkages among persons within the two systems. The stated commitment of the state's mental health department to providing services to persons with mental retardation and developmental disabilities within the most appropriate setting that meets these individuals' needs was very helpful. Our state plan emphasized prevention of institutionalization when inappropriate, improvement of institutional services, and placement of persons, who are inappropriately placed within the institutional setting, back into the community with appropriate support services -- all activities that helped guide our actions. We were able to use the plan's requirement for an array of living



arrangements and support services, as well as services in the area of vocational/volunteer programs, to help foster our own ends.

Making available cross-training opportunities improves the probability of success.

As a result of the state of Mississippi's plan and our commitment to cross-training, we have sponsored seven annual conferences which have addressed the needs of elderly Mississippians with mental handicaps. In addition, there have been six joint conferences on the elderly which were co-sponsored by a variety of public and private agencies involved in the provision of services. We learned that such cross-training endeavors can have a significant impact on the ways in which this population can be served, within other available services.

Involving the right kind of staff in implementing the program is very important.

We were most fortunate when recruiting staff who were to be involved in this particular program. They did not necessarily bring to the job professional backgrounds of either gerontology or mental retardation, but brought more important attributes of creativity, concern, compassion, and commitment to a job well done. The case manager for this program was a registered nurse who would also be an outstanding recreation director or competent in scores of other jobs. This commitment to helping people -- not a diagnosis -- is one reason that the program was successful in helping the participants to become more interdependent.

Parting Comments

Our experiences were not without some problems. There were a number of things that posed serious challenges to our efforts, among such as:

 Not being aware of the resources available and how to access them. However, being that so many individuals representing various service systems were involved in the development of the state plan, enabled us to be aware of formal as well as informal resources within the state for which our target group would be eligible.

- The lack of available slots within existing services. There was a delay in having certain adults access appropriate services due to a limited number of individuals who could be served. We have emphasized the importance of our adults having an equal right to services, rather than preferential treatment, as we wanted to do all that was possible for them to be perceived on an equal footing with other service recipients.
- The availability of funds when needed. This
 factor required the staff to be most aware of
 various funding sources in all areas of service
 delivery, ranging from those services provided by agencies within the federal government
 to funds provided by state, local and private
 sources.
- The acceptance of the seniors from our system as people and colleagues of other seniors in the community. In some programs we encountered resistance to our adults being accepted as equals. The supported psychosocial integration approach helped to alleviate this barrier, as was the reality that individuals referred possessed the social skills required to be included as a full member within that particular service. We also provided case management services, so that if a senior was experiencing difficulties within the service, it was possible for a representative from our agency to remove that senior from the service. Additionally, this approach enabled the service provider to keep our agency abreast of specific skills that needed to be developed further.

The primary beneficiaries of this project were the elderly individuals participating in the supported integration initiative and the generic senior services. With the emphasis placed on psycho-social integration -- in addition to physical integration -- the participants had the opportunity to live more meaningful lives during their retirement years. However, another outcome of this project relates to the continued collaborative effort implemented between the two agencies.



This collaboration enabled the provision of a wide range of services in the most appropriate setting, and avoided the duplication of services in both agencies.

Due to the unprecedented shortage of resources, there must be a keen awareness of the necessity of working together and that limited assets compel the continued development of an interdependent functional approach, rather than a more self-sufficient approach taken in areas where resources are more plentiful. The psycho-social integration approach described here involves little in the way of additional resources. Training was conducted by existing staff of the Community Services Department, with additional support provided through other departments of the Boswell Center.

An area of continuing need is the opportunity for cross-training of professionals in the fields of mental retardation and gerontology. This training is seen as essential in stimulating a continued cooperative working relationship between the two areas. Additional cross-training will continue to improve service delivery by enabling the staff of aging programs to feel more comfortable when providing services to aging individuals with developmental disabilities. Crosstraining also helps staff to view the individual who is elderly and has a developmental disability as a person first, and then as one with unique characteristics and needs. Finally, cross-training helps to instill the notion that advocates do best when they advocate for people, not labels.

Regional Council on Aging Brokering Project

Teresa Galbier1

Case Abstract: This case study describes the experiences of an aging network agency in Rochester, New York operating a services brokering project that aided seniors with a developmental disability with choosing and using senior center services. Case managers coordinated the services which were needed to help older persons with developmental disabilities to be integrated into senior centers. After four years, over forty-five individuals have been integrated into eleven senior centers successfully with the assistance of twelve senior companions, one part-time social worker and several volunteers.

Introduction

In October 1987, The Regional Council on Aging -- a private, non-profit organization with more than 27 programs serving the needs of older adults in New York's Monroe County -- received a three year demonstration grant from the New York State Developmental Disabilities Planning Council to develop a model that would facilitate the successful integration of older adults with developmental disabilities into community-based senior services in the greater Rochester, New York area.

Project Description

The project, called the Developmentally Disabled Elderly Program (DDEP) operates Monday through Friday from 8:30 a.m. to 4:30 p.m. The director oversees the operation of the program and supervises a part-time social worker and several senior companions, volunteers and college level interns. Depending upon the needs of the participants, various support services may be provided such as advocacy, crisis intervention, individualized and/or group coun-



Correspondence should be addressed to Teresa Galbier, Director of Developmentally Disabled Elderly Program, Regional Council on Aging, 79 North Clinton Avenue, Rochester, NY 14604-1471.

seling, peer support groups, information and referral, community awareness, and the arrangement of transportation to the senior program.

We were able to provide an age-appropriate, cost-effective alternative for older adults with developmental disabilities who wanted to retire from sheltered employment, highly structured day treatment programs or who had no programming but desired and needed age-appropriate programming.

Participants of the DDEP came from a varietv of residential settings. Twenty-one percent of the seniors lived independently, 18% lived in adult homes, 3% were in enriched housing programs, 6% resided in supportive apartments run by developmental disabilities agencies, 15% lived in developmental disabilities agency community residences, 8% resided in foster family care homes, 3% resided within the regional developmental center and 26% still lived with their family; 44% of the seniors are female and 56% are male. Twelve percent of our participants were aged 50 to 59; 41% were aged 60 to 69; 41% were aged 70 to 79; and 6% were aged 80 or older. Of the case load, 50% of the seniors had not been known to the developmental disabilities system prior to the referral to the DDEP.

The role of the DDEP program director was as a broker of services. Once a referral was made to the DDEP, the program director, and anyone else involved with the potential participant's care, were asked to participate in an intake meeting. The meeting was used to discuss the participant's desire to retire and the support services necessary to maintain him/her in a high quality community-based retirement setting. Once the individual and team decided on the services needed, the DDEP program director made the necessary connections with the needed services. Included in this category were transportation, senior companions, adaptive equipment, counseling, advocacy, dietary consultation and nursing services, as well as participation in a number of program sites within Monroe County.

Potential participants came from the following sources: residential programs within the developmental disabilities system which included supportive apartments, community residences, intermediate care facilities, family care homes and the regional developmental center, residential programs within the aging system which included adult homes, long-term care facilities, apartment complexes for senior citizens, and enriched housing; day programs within the developmental disabilities system which included day treatment programs and sheltered workshops; day programs within the aging system which included senior citizen centers, social and medical day care programs and senior nutrition sites; and other sources, such as legal services for the elderly, local churches, the county office for aging, family service programs, mental health outreach programs, religious and service organizations.

The criteria for participation included the following: the senior must be age 60 or older, have a developmental disability, the potential to be integrated into a community-based setting and not require more supervision than any other participant who does not have a developmental disability.

The senior center locations selected for potential participants included self-contained community centers, programs based in a church hall, programs located with other services for adults as well as children, and programs operated through town and city recreation departments. Generally, nutrition centers were selected for integration because they provided a hot meal daily, have on-site staff and a wide array of activities from which to choose. Transportation was generally provided through a contract with Monroe County Office for Aging or by a small donation from the rider. If participants needed wheelchair transportation, the DDEP program director sought other means of transportation which were more appropriate.

To recruit participants for the project, we sent letters to agencies that work with older adults with developmental disabilities. Included in these letters were a brief overview of the program, a definition of developmental disability,



the contact person's name and phone number. and the fact that the DDEP program director would be contacting them to set up a meeting to describe the program in more detail. We then telephoned the person who received the letter and asked him/her for a time when we could discuss the program with him/her and his/her program staff (this meeting included anyone who was involved in the care of the potential participants). We gave a presentation at the informational meeting of the program and its components and the criteria of potential refer-

If a potential referral was made from within the developmental disabilities system, it was fairly simple to retrieve the needed paperwork ---- which included a state-mandated standardized assessment instrument, a social summary, and a nursing evaluation. If an individual was referred from outside the developmental disabilities system, it was often necessary to retrieve information which provided documentation of a developmental disability. This task was generally achieved by contacting physicians, family members, local hospitals, neighbors, and anyone else who may have known the senior when he/she was younger.

Once the documentation was received, the following steps were taken: selecting of a senior citizen site according to its proximity to the potential participant's residence; making the necessary alterations to the building for it to be accessible; being sure that the services offered were relevant; being certain that the other participants accept the potential participant; being sure that program hours were adequate; making sure that transportation was offered and that the attitudes of senior center staff and volunteers were accepting, rather than rejecting.

We tried to recruit and train a senior companion for those potential participants who needed extra attention which could not be obtained from the other participants. We often recruited such volunteers by using a public relations campaign that was often carried out with the assistance of the state developmental services staff who oversee the senior companion program in our area. Once we located potential

volunteers, we screened and interviewed them. and then, once selected, we introduced the senior companion to the potential participant. If the agency, the participant, and the senior companion felt that the participant and the companion were compatible, we often scheduled a lunch visit for their first trip together to a senior program site and then set up a tentative schedule for the comparison to help the participant with his/her gradual integration into the senior center.

We found that the participant felt ready to be involved in programming after about a one month transition. Once both seniors felt comfortable with one another and the senior liked the program site, we scheduled a meeting with all who were involved with the participant's program plan. At this meeting, we usually developed and implemented a goal plan which was reviewed monthly by the DDEP program staff. If all was going smoothly after the second meeting, we then scheduled only annual reviews.

One senior companion was assigned two or three participants depending on the participants' needs. Sometimes two or three senior companions were assigned to a particular senior center where they worked as a team to provide attention to several participants with developmental disabilities. In other instances, senior companions were assigned to a senior center where they worked with up to three participants at a time. Occasionally, senior companions were used to assist participants to become integrated into a senior center program. The companion was reassigned to a new participant when it was determined that the participant no longer needed individualized assistance.

The DDEP program director was involved in a number of supportive activities which included program innovation, case management, advocacy, crisis intervention, timely evaluations and care plan meetings, community awareness and education, proposal writing, program assessment, reporting to the DDEP Program Advisory Board, maintaining budgets and record keeping, fund raising and public relations, establishing and maintaining collaborative relationships with



community organizations, especially those serving individuals with developmental disabilities and/or aging persons, and attending conferences and educational programs related to the program.

The job duties of the part-time social worker included a number of other types of activities which encompassed program innovation, group discussions, individual counseling, public relations and publicity, peer support groups, supervision and support to senior companions, and facilitating communications between participants, caregivers, companions and program staff.

Although senior nutrition sites serve only seniors at least 60 years old, we were able to integrate a number of other participants if they were accompanied by a 60 year old caregiver. They volunteered within the program for at least one half hour per day, or the senior center directors agreed to allow them into their program because they appeared to be older.

After four years of operation, more than 45 individuals have been integrated into 11 senior citizen centers with the assistance of 12 senior companions, one part-time social worker and a handful of volunteers.

Our project was funded by a grant for the first three years after which time, we received stable funding through a contract with the county by using funds from the local assistance program of the New York State Office of Mental Retardation and Developmental Disabilities and a matching funds grant from the Monroe County Office of Mental Health. The program cost was less than \$10.00 per day per participant. This rate included transportation, extra money for special activities, and program staff support.

Lessons Learned

Using a variety of agencies may be necessary to meet each participant's needs.

We found that we could draw upon a range of community resources to help carry out this project which included the Monroe County Office for Aging, transportation services, public and private human services agencies, state-operated facilities, volunteer organizations, community education and advocacy programs such as the American Red Cross.

Overcoming barriers is an ongoing process

Over the course of the past four years we have encountered a number of recurring barriers to aiding seniors with developmental disabilities in the integration process. These barriers have included problems with funding, problematic attitudes of staff within senior centers, overprotective staff at developmental disabilities programs, uncooperative family members or other senior citizens, problems with obtaining the necessary cash for the requested donation, and a lack of cooperation and communication between and among the agencies involved.

We found the ways to overcome these barriers included becoming involved with our local university affiliated program in developmental disabilities to provide training and in-services to staff, senior companions and interested consumers; instituting community education and awareness, presentations, conferences, seminars, inservices to the public, agency staff, colleges, health care professionals, corporations, health fairs; applying for grant proposals; fundraising; speaking at public hearings; and having our program become a part of the local government's long-range plans.

It is important to continue advocating for the needs of individuals with mental retardation within these agencies. With all of the awareness and education of people with disabilities, we have only begun to make a difference in their lives.

Parting Comments

The Developmentally Disabled Elderly Program of the Regional Council on Aging assisted over forty older adults with developmental disabilities in retiring to community-based senior services. Our methods included brokering services from existing community resources and molding these services to meet the needs of each individual participant. Once integrated into the community-based senior service, on-



going comprehensive case management was provided to the participants by the DDEP program director, social worker, senior companions, volunteers and student intern.

We found that our program provided us with tremendous learning experiences about outreach into the community. One reason for our success in outreach was that within our own agency, many of the parents and caregivers are also aging and being placed in hospitals or nursing homes and they were glad to hear that we could provide assistance to their family member. We also became a resource for other aging network programs which did not know quite how to provide for an older adult who they believe has a disability.

Our recommendations for others who are interested in developing a project such as this

one include:

- Remain as objective as possible when dealing with sensitive, awkward issues by collecting all information from all sources before responding.
- Be sure to gain support from the local office for aging and developmental disabilities service offices before proceeding.
- Always put the participants' desires at the forefront.
- Develop the program around each participant and what he/she wants to get out of the program.
- Focus on participants' strengths by building upon their ski'ls rather than focusing on their deficits.

Portland Senior Center Project

Betty Zachary¹

Case Abstract: This case study describes the development of a retirement screening program used to identify people for integration into urban senior centers in Portland, Oregon. The project promoted participant independence and found retirement need to be high and integration success limited by the availability of senior centers. A number of seniors with developmental disabilities were aided in adapting to the activities of local senior centers.

Introduction

The Portland Senior Center Project began in 1984. Its purpose is to provide leisure education, recreation, and other opportunities that enable seniors with mental retardation to be integrated into neighborhood senior centers. The project takes place in Portland and Multnomah County, Oregon. It emphasizes serving individuals who receive services in Multnomah County's activity center programs,

on the activity center's waiting lists, or residing in nursing facilities within the county who could benefit from learning how to use the activities in our community's senior centers.

A fundamental tenet of the Senior Center Project was that its activities should be conducted consistently with the concept of "normalization" and the provision of a growth-oriented high quality lifestyle for each participant. We wanted the senior center sites to provide each



Correspondence should be addressed to Betty Zachary, CTRS, City of Portland, Bureau of Parks and Recreation, Senior Leisure Services, 426 NE 12th Street, Portland, OR 97232.

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participant with a variety of opportunities that can aid in expanding his/her capabilities. We believed that each participant can be afforded the highest opportunity for success when his/her program content is appropriate and achievable as well as consistent in delivery, holistic in scope, and designed to be delivered in a normative manner.

The identified service goals of the Portland Senior Center Project were as follows:

- to provide appropriate, integrated social/recreational opportunities;
- to provide assistance to community senior centers;
- to develop a model program for successful integration for the older citizen with a mental handicap;
- to create additional activity center openings for those on the waiting lists;
- to increase social interaction skills;
- to foster the development of a personal awareness of leisure;
- to advocate for the rights of each participant;
 and
- to provide leisure education with respect to each participant's rights as a citizen.

Through their participation, the seniors become more active members of the community with the expectation that they are afforded a greater opportunity for personal growth. With this thought in mind, participants' goals were measured by the following criteria:

- » Do the services provide respect for the participant's right to a normal rhythm of the day while at the center?
- » Do the services rendered provide for the greatest scope of resources the community has to offer?

- » Do the services offer the participant the ability to make choices?
- » Do the services provided enable the participant to be creative?
- » Does the senior center environment afford the participant the opportunity to form bonds with fellow seniors at the center?

Project Description

The Portland Senior Center Project was jointly sponsored by the Multnomah County Office of Human Services, the Social Services Division of the Developmental Disabilities Program, and the area agency on aging. It was aided by the Portland Bureau of Parks and Recreation Special Recreation Services Program with the support of a number of local social and senior service agencies. The Project is funded by an annual \$19,000 base grant from Multno nah County. An additional \$25,000, added to the Project, permitted us to hire additional staff to assist with programming. Staff consisted of a director, supervisor, part-time coordinator and two volunteers.

On the average, the program served about 13 participants with mild mental retardation over a one year period. Each of the participants attended his/her local neighborhood senior center where he/she was involved in center-based recreational and social activities.

The Multnomah County Mental Retardation/Developmental Disabilities Program subcontracted with a number of agencies in the area to operate activity center programs to provide five day per week vocational, social, recreational and self-care training to adults with mental retardation. The waiting list for these services was quite lengthy. Of the people on the waiting list, 19 were age 55 to 59, and 19 were between the ages of 60 and 81.

When we became aware of the length of the waiting list, we felt that it was time for some of these people to retire, like other persons their age. Without some training and assistance,



however, it was obvious that retirement for these people meant being trapped at home with nothing to do. Our initial program idea was quite simple: We wanted to provide an ageappropriate activity service alternative and to provide a means to a normal experience of retirement for these individuals. Thus, the concept was formed to assist aging individuals in joining their age group peers in community senior centers and meal sites with the aid of our program aides.

We felt that this approach would positively impact the individuals served as well as the participating agencies. The older adults with mental retardation would be enabled to participate in the normal rhythm of the life cycle through retirement and linkage with services and activities common to their age group. Additionally, the retirement of individuals currently in activity center programs and/or on the waiting list for those services would create vacancies in activity center programs which would enable individuals on the waiting list to move into programs more quickly.

Our process was simple. Applicants were pre-screened prior to placement on the waiting list. When a vacancy occurred in the Project, the waiting list was reviewed in light of the established criteria and priorities. Care was taken to assure that highest priority individuals who needed services were served first and that support would be available both during and after Project participation.

lnitially, these individuals participated on a 30-day trial basis. If by the end of this time it was determined that a community senior center was not an appropriate placement, or if the individual decided not to continue participating, it was possible for the individual to return to his/her previous placement in an activity center or to the activity center waiting list. If an individual continued past the 30-day trial, he/she passed through the following four steps that lead to independent participation.

Step 1 -- the participant attended his/her local senior center with the supervision and support of the Project Coordinator one to five days per week. During this time, the participant learned about the senior center and learned to participate in the available recreation and leisure activities, with the assistance of the Project Coordinator, senior center staff, and other senior participant.

- Step 2 -- the participant continued as in Step 1, but was able to participate with gradually less support from staff. During Steps 1 and 2, the senior's evaluation and the planning/training system common to all activity centers was used for all project participants. The participant, case manager, home provider, family members and advocates were all involved in the development and implementation of goals.
- Step 3 -- the participant attended his/her center as many days per week as he/she desined (most attended between three to five days). Project staff made follow-up contact weekly and provided other assistance as needed or requested. Primary support from this point on was from senior center staff and participants, home providers, and family members. It was at this point that another individual was permitted to start his/her 30-day trial period and begin the process anew.
- Step 4 -- to promote greater independence, the participant attended and participated on his/her own with periodic follow-up by the project staff. Orientation, support, and advocacy were provided during all steps as needed by Project staff to participants, family, home providers and senior center staff to help make the process and transitions as smooth as possible for all involved.

Lessons Learned

Monitoring the participants at their respective sites is a difficult task.

We had six senior centers in the county serving 13 participants. Monitoring these participants at their respective sites proved to be difficult because of the number of sites and the distances between the different sites. When we increased the number of staft, this became less of a problem.

Limits in programming are difficult to overcome.

Many of the participating senior centers offer little or no programs other than serving as



meal sites. The plan for the future is to operate "core centers" that not only serve meals but offer a wide range of programs. This plan could present problems for the project such as transportation for the participants to and from the centers, and ultimately the neighborhood center concept could be a thing of the past.

Parting Comments

The Portland Senior Center Project was successful in providing a worthwhile experience for a number of seniors who could independently use the activities at a number of senior centers. All of the participants were actively engaged in activities within their centers.

Volunteers, recruited through a program called Serving Others Through Leisure Volunteer Experiences (SOLVE), contributed a variety of skills at the senior programs. For

example, one volunteer taught "creative chair exercises" at one of the participating sites four times per week; an-other volunteer assisted in half-day van trips and another volunteer did one-on-one reading skills with participants. Other volunteers at the various centers made a strong effort to engage in socialization and recreational activities.

The contradictory aspect of this program is that the waiting list continues to grow. There are approximately 800 individuals who have requested day programming and who are not being served. Of these 800, there are 19 individuals who are 60 years of age and older who have not been exposed to the Senior Center Project. Our limited resources mean that we can only serve so many seniors each year. Hopefully, those seniors who meet the criteria for the project will be given the opportunity to become involved and actively integrated members of their communities.

AVSP's Senior Integration Program

Maureen Brennick1

Case Abstract: This case study describes a retirement assistance project on Staten Island, New York that was run jointly by a developmental disabilities and an aging network agency. The project grew from a disability agency's social model day program after many of the seniors were thought to need a broader range of activity options. It was found that integration into senior centers and other activities could be aided, but not without problems related to lack of social awareness and limited experiences.

Introduction

A Very Special Place, Inc.'s (AVSP) Senior Care and Activity Center opened its doors in May 1987 to serve a number of adults aged 55 and older who had developmental disabilities. The Center's goal was to offer a discreet program that provided for retirement needs. The program's objectives were the enhancement of

socialization and leisure skills and maintenance of personal and functional abilities.

The Center was developed in response to AVSP's recognition of a need for retirement alternatives for seniors with a developmental disability. This need corresponded to what we were hearing from the greater Staten Island community and what was identified in the New



Correspondence should be addressed to Maureen Brennick, Director for Family Support Services, A Very Special Place, Inc., 1429 Hylan Boulevard, Staten Island, NY 10305.

York City Department of Mental Health, Mental Retardation and Alcoholism Services' Annual Plan. We felt that this program would offer a range of services that offered normal community alternatives for this population based on their individual strengths and needs. Most people without disabilities have the opportunity to consider retirement choices — we reasoned, why not seniors with a developmental disability?

The Center's efforts were twofold: conducting outreach to locate unserved or underserved seniors and aiding seniors by providing services and activities in a social model adult day care environment. As we proceeded with Senior Care and Activity Center and continued our outreach efforts for this program in the Staten Island community, other concerns came to our attention. For example, some of the seniors in our program appeared to be ready to move to other types of settings and activities. Additionally, there were a number of seniors in disability-specific programs who seemed to be in need of retirement options, but were either unwilling to attend the Senior Care and Activity Center or did not need the intensity of services that our program provided.

According to a report issued by the state, we knew that estimates of the number of persons with developmental disabilities over age 55 showed that there would be a significant group of seniors not receiving retirement assistance services who possibly needed them.

Project Description

Thus, a Senior Integration Project under the auspices of our Special Senior Network, seemed to be the perfect opportunity to enhance the existing spectrum of services. A Very Special Place, Inc. submitted a proposal in response to a request for proposals issued by the New York State Developmental Disabilities Planning Council. Funding for the project was approved and we were asked to operate the project jointly with another Staten Island agency that had also applied -- the Community Agency for Senior Citizens (CASC).

The project, to be carried out jointly by our two agencies, was located on Staten Island, New York -- one of New York City's five boroughs. Staten Island, a residential community of some 379,000 people, also has light industry and other commercial resources that support its economy. Staten Island is ethnically diverse, but is also very neighborhood bound and each senior center's members generally reflect the character of the neighborhood in which it is located. Not as densely populated as the other boroughs, it does nonetheless have a significant population -- much of it elderly.

Thus, our Senior Integration Program was born with the objective to provide outreach and retirement assistance. As a first step in the project, administrative staff from both AVSP and the Community Agency for Senior Citizens met to work out an approach through which we would proceed in identifying individuals and services/senior centers who could best benefit from and participate in an integration project. Because AVSP was primarily an agency serving persons with developmental disabilities, it was agreed that we would be the lead agency.

The project proceeded in three preliminary steps:

- Step 1 -- assessment tools were developed to help understand the ecologies of the various community agency program environments and were utilized in various settings that included disability specific and generic senior services.
- Step 2 -- an extensive community outreach was conducted via presentations to local councils and organizations, meetings with senior citizen and developmental disability agency representatives, and mailings to churches, synagogues and various other groups to inform the community of this project and to request referrals.
- Step 3 -- staff visited a variety of senior services/centers in order to have first-hand and accurate information about the services/ activities offered (see box). These visits



helped us to determine the appropriateness of the senior center services for those with special needs as well as their willingness to integrate people with developmental disabilities.

As the next step, we tackled a massive education and orientation effort throughout the Staten Island community agencies working with senior citizens and adults with developmental disabilities. Our targets were both generic senior centers in a variety of communities and seniors with various disabilities in various types of disability-based programs or at home with family members. Training was done as well in many different types of settings including senior centers, our own senior program, sheltered workshops and in any community setting that was willing to make space available for our presentations.

"... we encountered some resistance to change on the part of some of the seniors who might have been candidates for our project. We found many of them afraid to retire because of a potential loss of income, of not knowing what to expect from the changes retirement would bring, and of the loss of their identity as a 'worker'."

In this initial phase of our project, however, we encountered a number of unexpected barriers. The most significant was the difference evident between the aging network and the developmental disability system. We found that within the developmental disabilities system, the treatment philosophy is one of active programming and the role of staff is to insure participation of the individual via various programmatic interventions. Much of this problem stemmed from the philosophical and pragmatic orientation of working with individuals with mental retardation.

In contrast, to the aging network programs, the programmatic philosophy is more on staff involvement on an as-needed basis. Senior citizens are encouraged to participate, but if they choose not to, staff take a less active role. Simply explained, this is because individuals with mental retardation generally have a greater level of need for intervention due to cognitive limitations. These differences in treatment philosophies dictate level of service and staffing, and, therefore, the types of interventions and expectations of participants.

Extensive outreach meetings between our two systems and inservice/sensitivity training assisted us in understanding the differences and helped put certain mechanisms in place to assure a positive working relationship.

Another barrier we encountered was a lack of understanding by much of the generic senior citizen system of people with developmental disabilities. We found that this barrier was based on fears, stereotypes and limited experiences with individuals who had disabilities. In addition to training, we found that the most effective method to deal with this situation, was to introduce seniors with a developmental disability to their age peers via visits to senior citizen centers. We also sponsored events at our own Senior Care and Activity Center and invited seniors from other centers to attend. In this way, the two groups got to know each other, helping to overcome some of those "old" stereotypes.

Another barrier, unfortunately from the developmental disability system, was a problem with obtaining referrals for participants in the project. We found reluctance on the part of some developmental disabilities providers to refer some of their clientele. This reluctance appeared to stem from protectiveness towards their clientele and a possible aversion to change. Ongoing meetings with agency representatives and continuing individual contacts with these providers helped to some degree as referrals became somewhat more forthcoming. However, we found that outreach efforts had to be continuous or we would lose our momentum.



What to Look for When Assessing a Senior Center

- · is the building accessible (street level access or ramps)?
- is lighting sufficient?
- · is temperature seasonably comfortable?

✓ Access to public transportation

- is paratransit available?
- · are public bus stops, subways, or rail stops nearby?

✓ Program/activities

- is there a monthly calendar?
- what are the daily and special activities at the center?
- what are the sizes of classes?
- · how receptive is the instructor of class to

🗸 Meals

- can the center meet special dietary requirements?
- · what is the expected donation? how is it handled?

✓ Center culture

- how are first time users treated?
- · how do center members react to newcomers?
- · how are seats assigned at activities and lunch?

✓ Center size

- how many users/members are there?
- · what is the physical size (are there different spaces, quiet areas, group activity areas)?
- · what is the daily attendance?

Staff and volunteers

- how many staff and volunteers are there?
- · how familiar are staff and volunteers with disabilities?
- what are the attitudes of staff and volunteers toward people with disabilities?
- · is there a willingness of staff to "go the extra mile" to aid seniors with special

- · are the bathrooms accessible (accommodate wheelchairs)?
- is signage functional?
- are vans/cars available from volunteer transport agencies available?
- are taxis or private car services affordable?

having people with disabilities in class?

- how difficult are the tasks involved in the activities?
- are there eligibility criteria or costs associated with the activity?
- how many meals are served a day?
- how many people are seated at each meal?
- what is the reserved seat policy?
- how diverse is the ethnic composition at the center?
- what is the general atmosphere at the center?
- · what are the center's amenities (activity rooms, recreation facilities, etc.)?
- · are other people with noticeable disabilities attending the center? how many? and how do they manage?

needs?

- how do staff and volunteers interact with seniors at the center? (are members treated courteously? do cliques dominate? who makes decisions?)
- · were you made to feel comfortable?

Developed by Robert Goodman and Maureen Brennick



Additionally, we have encountered some resistance to change on the part of some of the seniors who might have been candidates for our project. We found many of them afraid to retire because of a potential loss of income, of not knowing what to expect from the changes retirement would bring, and of the loss of their identity as a "worker." Project staff worked diligently to address these issues, specifically by conducting pre-retirement workshops and by arranging visits for some of the seniors to the aging network and disability-specific senior citizen program sites.

Some Comments

Ms. Frances V. and Mr. Burt P. attend different community senior centers full time on their own. They travel to the centers on their own. ASVP provides some occasional monitoring.

Ms. Helen C. and Ms. Pauline B. attend several local centers for one day a week, accompanied by a staff member who looks out for them, but allows them to be on their own.

Twice a week, Mr. Ted D., Mr. Frank M., Ms. Angelina F., accompanied and assisted by a staff member, participate in a craft group at one of our senior centers; another group does the same at a different center.

Our "Luncheon Club," made up of ten seniors travels once a month to another center for socialization with the center's members. They are accompanied by two staff.

Lastly, an unexpected barrier that our agencies reported a few months into the project was our own limited definition of integration. At the initiation of the project, we assumed that our successes would lie in identifying candidates for full unsupervised movement from our system into the aging system. However, the number of people with skill levels that would permit full unencumbered movement were limited and therefore this severely restricted us. It took con-

siderable reevaluation and sharing of experiences with similar projects in other of New York City's boroughs to broaden our perspectives.

An opportunity then presented itself to include a greater number of seniors in the project. Hence, over the course of a number of months, with the ongoing identification by CASC of new integration sites, AVSP developed a more diverse program with candidates of varying needs as noted in the accompanying box.

As we worked with our program participants -- observing them interact with non-disabled seniors in a center not specifically designed and operated with the needs of people with mental retardation in mind -- we began to learn more about the problems of true integration. Our purpose was not to have people participate in this project without feeling and being as actual members of the centers they were attending. To become "mascots" or a special project of a particular center was not the goal of our project, nor did we believe that this would be an indicator of success.

Hence, it became clear to our staff that more training of our candidates was needed to facilitate their adjustment to the Center's demands. We realized that many of the seniors we attempted to integrate did not know the Pledge of Allegiance (which is said daily in many senior centers), nor did they know many of the patriotic songs regularly sung in the centers. Quite a few of them ate their meals without looking up at or speaking to others. They walked through swinging doors without checking behind them to see if anyone was there and at times did not realize that their chairs were blocking others' passage. These and other social behaviors, we took as "givens," were not always within the behavioral repertoires of the seniors we were trying to integrate.

These and several other seemingly incidental issues were barriers to acceptance; which set them aside without the staff knowing why. Our staff then began to address these issues and continue to do so via special training groups at the Senior Care and Activity Center. Obviously,

we are gaining more experience and knowledge

Lessons Learned

as we proceed.

Teaming a developmental disabilities agency with an aging network agency works well if your objective is to influence the aging network's programs.

We found that as part of a greater community effort to promote integration of the two systems, we were able to be that much more effective because we worked closely with an aging network agency. Our joint presentations and work at promoting community liaisons was effective because, irrespective of the allegiance of the agency, they saw us working as partners.

Don't assume that all seniors who have been in the developmental disabilities system for most of their adult lives have the social skills to function independently in senior center environments.

One of the more significant findings was the realization that many of the seniors for whom we advocated and worked, didn't have the functional and adaptive behaviors that would have let them blend normally in within the social ecology of the senior centers. Many had to spend some time in transition to gain social and communication skills.

We suspect that living one's life in a unitary environment -- free of the demands of competing influences and social needs as are developmental disabilities program settings -- doesn't prepare a senior for the social expectations of community senior center sites. A supplemental training program or at minimum phased exposure would go far in teaching new social skills.

Providing the groundwork for integration efforts, by education cumpaigns and personal contacts, is crucial -- particularly in areas of ethnic or cultural similarity.

It was our experience that we could not just assume that each senior center site would be naturally receptive to our overtures. We carefully planned and implemented a preparatory

campaign to orient and introduce the notions of acceptance and integration. Tight-knit communities can be overwhelmingly difficult for integration efforts or, if the right people are gotten to, they can be the most facilitative.

We carefully chose our course of action depending upon what was the character of the organization we planned to approach. This approach was particularly important in communities where different ethnic and cultural enclaves existed.

Parting Comments

As the Integration Project moves into its second year of funding and activities, we are now reviewing our prior goals and objectives and those activities we undertook. Last year's goals were appropriate and they were generally met. We believe, however, that approaches to the community need to change. Resistance to new ideas continues to exist.

Although we know that referrals would not come easily, we assumed that we could overcome that obstacle. As yet, that has not occurred and it is apparent that much of the mental retardation/developmental disabilities field needs to become more creative and openminded about new ideas for the elderly.

We also underestimated the fears that people with developmental disabilities had about the concept of retirement and the enormity of adjustments they have to make for that time. Their fear of loss of income is real and as yet, the system cannot promise them that more money will be available to them. However, it has become evident that systemic change is needed in many areas. We can distribute SSI monies differently to allow seniors more choice in how their extra dollars are spent.

We can also educate people who work with program members with a developmental disability to understand that their clientele have the right to a tirement options, as do all citizens. It is important to expand programmatic options to include semi-retirement alternatives and retirement counselling. It is crucial for the commu-



nity to continue to look at its own prejudices and fears and be open to change. People with developmental disabilities and other handicapping conditions do have the right to participate in their own community to the best of their ability. It is hoped that through the Integration Project and the Special Senior Network our experience and understanding will nurture the growth of a responsive, need-based, creative senior service system.

Silver Streaks

Marion M. Balch¹

Case Abstract: This case study describes a senior club set up within a developmental disabilities agency in a rural area of upstate New York. To help older employees of a sheltered workshop transition to retirement activities, the club model was used to empower the seniors in decision making, taking part in other senior activities, and becoming an active part of the community aging network. It was found that a low cost option, like a senior club, can help to prepare seniors for retirement, open up new opportunities, and serve as a vehicle for involvement in the greater community.

Introduction

In the mid-1980s, the Lexington Center, Fulton County's Chapter of the New York State Association for Retarded Citizens, Inc., began to take notice of the increasing number of older individuals working in the agency's sheltered workshop and other work programs. While the population of the agency's work programs disabilities included various physical disabilities and mental illnesses, the vast majority of the workers were adults with developmental disabilities. Many of the individuals with developmental disabilities were among the first in New York State to have been deinstitutionalized and, as a result, have lived successfully in the community for many years. Others have always resided in the community. Currently, they live in agency-run community residences or intermediate care facilities, while others live on their own in apartments in the community or with family or friends.

What was common to all of them was their involvement at Lexington Center's sheltered

workshop in Johnstown. For most of the seniors, the workshop was the only option for day time activities. Over the years, earning a paycheck had been stressed so successfully that any other activity was devalued. Generic senior services were available in the community, but little was known about what they were or how to access them. Even if individuals had wanted to participate in more age-appropriate activities, the generic system was ill-prepared to accept them.

During that time, a fledgling attempt was made to begin accessing community senior services. Working with the director of the local Office for the Aging (OFA) nutrition site, arrangements were made for the workshop's older workers to attend the meal site one day per week. At first only two or three people participated, but over time, this number grew to an average of 15, some of whom now attend more than once a week.

Transportation to the meal site was provided by an OFA van. Initially, a retired workshop



Correspondence should be addressed to Marion M. Balch, Director for Rehabilitation Services, Lexington Center, 465 North Perry Street, P.O. Box 440, Johnstown, NY 12095.

Casebook of Program Ideas in Aging and Developmental Disabilities

supervisor accompanied the group. Quickly, this became unnecessary as participants began to instruct each other on proper procedures.

Project Description

As a result of this initial integration effort, it became clear that something had to be done to provide age-appropriate and integrated choices to the workshop's seniors. In the spring of 1988, Lexington Center applied for grant funds to create a senior coordinator position which focused on introducing seniors in our workshop to age-appropriate programs. Unfortunately, these funds were not received.

By early 1990, the agency decided to try providing some degree of services to this group with whatever resources it could muster. In March, a meeting of all interested older workers was scheduled by a workshop counselor. It was in this way that the workshop's senior club, the Silver Streaks, was born.

"The Silver Streaks Club is not a product but rather one step toward the ultimate goal of meaningful choices and experiences for seniors with developmental (or other) disabilities. The club has become a vehicle for promoting self-worth, empowerment, and fun, both in integrated and non-integrated activities."

The Silver Streaks is a senior citizens' club like other senior clubs, with one difference -- its members are sheltered workshop workers and its meetings are held at the sheltered workshop. After nearly two years in existence the club now has 41 members: 22 men and 19 women. Thirty-two members have developmental disabilities, five have physical disabilities and four have mental illnesses. The ages of the members

range from 49 to 74; five are under 55, 32 are between the ages of 53 and 69, and four are 70 years of age or older. The younger members have been included because their needs and interests have prompted them to request membership.

At the initial meeting, the group members displayed only a casual interest. They discussed how they felt about working, and if they wanted to do other things. Very few ideas surfaced beyond working. The next meeting was held in May. At the May meeting, the director of the Fulton County OFA spoke to the group members and welcomed them as a new senior club. In addition, she offered to provide them with recreation funding once they became organized. Suddenly, the group began to perceive itself as empowered. They felt important and worthy of outside recognition and support.

From that point on, the club has held monthly meetings. After much discussion and voting a name was chosen: *The Silver Streaks*.

A number of club officers were elected in September, including a President, Vice President and Club Advisor. During this time, the club issued press releases about its activities. As a result of these press releases, the club's officers received an invitation to join the Fulton County Council of Senior Clubs in October. The council is made up of representatives from all 14 senior clubs in the county. The Silver Streaks' officers now attend council meetings regularly to report on club activities and to participate in Council planning activities.

Membership cards were designed and distributed. The club applied for and received \$200 in recreation funding from the Office for the Aging, which it used to fund transportation to special events.

After the initial meeting, club members saw new options for themselves. They began to express their own wishes and desires. In fact, once the group got started, staff were hard pressed to keep up. Members' ideas have included from camping, trips to Atlantic City,



raising funds for animal shelters, and visiting a greenhouse.

During the past 21 months, the group has participated in a wide variety of activities including monthly club meetings, inviting guest speakers to various meetings (from OFA, various businesses, local elected officials), attending OFA sponsored bowling groups and picnics, visiting malls, going to the Saratoga Harness Track, attending library programs, county fairs, art shows and a cider mill, running a booth at the OFA Garage Sale, forming a choir and performing for local nursing homes and attending the funerals of several members.

In May 1990, the agency again applied for, and this time received, grant funds to implement programming for seniors with developmental disabilities. Due to state budget problems, these funds were not available until the fall of 1991. At that time, a senior program coordinator and part-time assistant were hired. While the majority of their time is dedicated to operating a parttime senior day program, conducting consumer find, and coordinating with the local OFA, a portion of their time is earmarked for providing organization and direction to the Silver Streaks. As a result, the club is now holding weekly activities. Although not every member participates in every activity, there are weekly choices about activities to be made. Some individuals prefer to work except when there is a mall trip. Others take every opportunity to try something new. In order to keep up with all of this activity, we have created a Senior Bulletin Board in the workshop. On it are posted the nutrition site menu for the month, meeting notices, photographs from recent outings, OFA news items and other articles of interest to seniors.

Lessons Learned

Senior clubs can be run on a shoestring, although any monies contributed are helpful.

The Silver Streaks received OFA funding for 1990 only. Even then, the \$200 received was quickly depleted. Funding for this program has since been a combination of agency sup-

port (for such things as transportation, staff time, refreshments, etc.), fund-raising events by the Silver Streaks (food sales) and member contributions. For example, when the club went to the county fair, transportation and staff time were supplied by the agency, admission tickets were purchased with club funds, and any refreshments or other items were paid for as desired by the individual members.

Aside from funding, the club has received many other types of support. The workshop's production manager has had no qualms about losing his older workers during club meetings and outings. Indeed, he has been very supportive, making donations of excess production materials and supplies to the club. The agency's recreation director also serves on the county's OFA staff. She has contributed many hours to the planning and executing of activities for the club and has been a prime force in creating integration opportunities.

Other staff members throughout the agency have contributed ideas, time, materials and skills to assist with club activities. Participants from the agency's Office of Mental Health certified Continuing Treatment Program volunteer weekly as bowling score keepers and also assist at club fund-raisers. The local OFA staff have served as valuable sources of information and assistance and are committed to the success of this group.

Age peers are useful as role models to "break the ice" in community activities.

Throughout the development of this project, various choices were made which facilitated its success. When individuals were first introduced to the nutrition site a retired staff member accompanied the group instead of a young staff member. When selecting an advisor for the club, a twenty-five year veteran staff member, a "senior" herself, who had the respect and trust of all our workers, was chosen. The agency cultivated and nurtured its long-standing positive relationship with the county OFA and its director. For years the agency has been actively involved on several county-wide committees concerned with long-term care services.

A senior club model can be a useful device for sharing activities and community resources.



When attending integrated community activities, we have attempted to blend in, without drawing attention to, the disabilities of our members. We have also made sure that in whatever way possible, we have given back to the community's seniors. At last summer's county-wide OFA picnic, Lexington supplied tables, chairs, coolers, a coffee pot, a popcorn machine, and a supervised crew of summer youth employees to help set up, serve, and tear down.

Parting Comments

Although the Silver Streaks participated in many activities, the cost of those activities is prohibitive for some members. For those living independently or with family, the cost of bowling or a boat ride is beyond their means. Consequently, the club plans few activities that require a fee, thus limiting its range of activities.

Fulton County is an economically depressed area. There are two senior centers and five nutrition sites in the county and a limited transit system. These factors make it difficult for workshop seniors to attend community senior activities. By having a senior club at the workshop, we are able to introduce individuals to outside activities and to transport them as a club, but we have great difficulty in arranging transportation for them to participate independently.

The Silver Streaks Club is not a product but rather one step toward the ultimate goal of meaningful choices and experiences for seniors with developmental (or other) disabilities. The club has become a vehicle for promoting selfworth, empowerment, and fun, both in integrated and non-integrated activities.

Our biggest regret about the Silver Streaks project is that we did not start it ten years sooner. The lesson learned is do not wait for a funding source, do not try to put in place a grand scheme — start with what you have. If you want a program for seniors, there is probably some small thing you can do right now. Our experience has shown that after you do that small thing, people will begin to notice and get in line to help. Build on the strengths and abilities that your agency has. Use whatever connections you have already established.

At the Lexington Center, the Silver Streaks Club has empowered our seniors, raising not only the members' self-esteem, but the esteem of their co-workers and friends. The group's energy, enthusiasm and drive have focused staff, agency, and community attention and resources on the needs and abilities of this so long overlooked group of individuals.



A unique concept in providing retirement activities opportunities is the notion of "pull-out" programs. During the course of collecting examples of projects designed to aid integration and socialization, we came across a number of these types of programs. What are pull-out programs? They are programs where two or more groups of people are drawn together for a common purpose during a distinct period of time. In many instances, the host program may operate a specific site, such as a senior center, or a disability agency retirement program. The operators of each agency will schedule common activities that facilitate the interaction of members of each program with those members of the other program. Sometimes these programs are designed around a one-time activity like a visit or trip, other times around an on-going activity like maintaining a garden or a travelling chorus.

What is the benefit of such programs? They tend to bind people of different backgrounds or affiliations during a period of time when each person can get to know the other better -- the goal in each case is to "break down the barriers" and let natural friendships or social contacts to evolve. Sometimes these efforts are successful to this end; other times, they offer a period of common camaraderie which is then followed by each going back to their own. Do they have a positive effect upon their participants? We think so. The examples that follow show that psychological barriers can be broken down, and that people can get to know other people so as to allay stereotypes or negative impressions. These models are not unique, but that they are being tried in greater frequency speaks well to the creativity of people working with seniors to break down social barriers.

The lessons learned? Creativity and innovation often must struggle with lack of financing and administrative problems. Such programs can only work when an individual "spark" sets the tone and oversees the workings. They are excellent "ice breakers" in getting the community to think in terms of inclusion. They are an excellent means of fostering friendships and greater public awareness of people growing older with disabilities.

Section 4: Pull-Out Programs

Syncopated Seniors

Beth Zimpel and Natalie Heretz¹

Case Abstract: This case study describes a project which took place in a rural area of New York state that used a spirited chorus group to bring together seniors with a developmental disability with other seniors from the same community. Both shared in learning new songs and travelling about to meet singing engagements. Social bonding and shared learning lead to new friendships and greater community acceptance of older persons with developmental disabilities.

Introduction

Performing arts are an ideal community integration medium for elderly persons with developmental disabilities. At the Oneida County Association for Retarded Citizens we discovered this happy fact, almost by accident. Since 1988, we have been networking with the Comhill Senior Center in Utica, New York. Our seniors and the seniors from the local developmental disabilities service office were going to the Center for various shared activities, such as lunch, bingo, field trips and special events. Members of that Center were also coming to our facility to learn more about us. We wanted to put a little more "pizazz" in the process. Thus, we came up with the idea of combining the two groups into a chorus.

Through this many goals could be achieved:

- Provide an integrated activity that both populations would enjoy in a generic senior center setting to enhance a retirement lifestyle.
- Serve as an example to the community through our local performances that these two populations can work harmoniously together and produce something of value.
- Raise the community consciousness that the aged, both generic and those with developmental disabilities, have a valued presence in our community (22% of our local population is 60 years old or older).
- Give the performers an chance to give back to the community that has given to them.

Project Description

Everyone agreed that this idea was an excellent one and worth a try. As far as we were aware, the chorus would be the first one of its kind. Groundwork was already in place through an earlier effort to bring the groups together. (In 1989, the NYS Office of Mental Retardation and Developmental Disabilities published a report on these efforts titled Sharing Activities.) General support in our community was also well established as far back as 1986, when the Oneida County Association for Retarded Citizens spearheaded the formation of a task force to study the emerging needs of the elderly persons with mental retardation and developmental disabilities. Involved in the founding of the task force was the Institute of Gerontology at Utica College of Syracuse University and the Rome area developmental disabilities service office. The county office for the aging is also a major participant in the Task Force -- now known as the Oneida County Aging and Mental Retardation and Developmental Disabilities Coalition (see Section 2 for a fuller description).

In March 1990 we began chorus rehearsals, practicing one hour per week at the Cornhill Senior Center. Fifteen members of the Center participated, as well as six seniors from the OCARC and three seniors from the Rome developmental disabilities office. The community performances started in June 1991.

In one year, we have "sung out" twenty-five times at various places including nursing homes, senior centers, local college activities, and community events.

Supporting this very complicated, but excep-



Correspondence should be addressed to Angela Z. VanDerhoof, Executive Director, Oneida County Association for Retarded Citizens, 14 Arnold Avenue, Utica, NY 13504-4759.

tionally popular singing group are two staff from OCARC (one for coordination and one for conducting), two staff from the Rome developmental disabilities office, OCARC Transportation Department, Cornhill Senior Center (space and membership), the state developmental disabilities agency's Senior Companion Program with two volunteers, and most important and difficult to recruit, a volunteer piano accompanist.

"Probably the single most important ingredient is to have one person willing to take the lead who sees this goal as a worth-while effort no matter what the barriers."

The process of setting up the chorus was a step-by-step one. Through word of mouth by key active center members, support was given to form a chorus. Signs which advertised the formation of a chorus to sing "old time tunes," were put up at the center and notices were placed in the monthly calendar of events. A volunteer piano player, who is also a senior, was found through a request in a local church bulletin.

From the onset, the facilitator sought to have the membership understand that the philosophy and goal of the chorus would be to focus on the group's process and the members' relationship with one another. The music would be secondary. As a result, the caring attitudes and respect afforded to everyone and acceptance of individual differences has produced a well orchestrated chorus that is an appreciated group in the community.

Dignity in everything we do and how we present ourselves has also given the chorus a valued artistically successful image. The chorus members are often reminded of this philosophy and thanked for the important contribution they make toward meeting these goals. Role modeling and peer pressure reinforce appropriate

behavior and the Senior Companions also play a vital role in this area. We attempt to encourage participation and an interdependent relationship among the groups which is positive, valuable and mutually rewarding.

The songs are ones that are familiar and commonly heard today. The first verse is played through by the accompanist and then sung by the chorus. Because some individuals with developmental disabilities may not read, this offers more opportunity to participate, as the words to the first verse are more likely to be remembered. The non-reading seniors are always offered a songbook and help is provided by a center member in finding the correct page.

The center members who have visual acuity limitations are given large print copies of the lyrics. Support is given to everyone who needs it, in whatever form is necessary. For example, a woman with a developmental disability who is in a wheelchair does not have access to the stage where the practice sessions are held. She has, therefore, been made assistant director and places herself off stage where the conductor of the chorus stands.

After a person with a developmental disability has participated for about three months, they are replaced on a rotating basis by another member. This switch is done at a time when the selection of songs is changed to afford the member ample time to learn the music and routine of the group and to maintain the continuity of the chorus. During concerts, the chorus members wear white shirts/blouses and black pants/skirts. The women wear a red vest while the men don a red bow tie. This common attire helps give us a visual identify and unified appearance.

Partial participation in the activity is valued. For example, one member of the chorus had a severe hearing limitation and sings very few words to the songs. However, she adds much spirit and love to the group and receives immeasurable pleasure in return. The chorus members are valued because of their humanness, not for what they can produce or do. Because the re-



quests for engagements were more numerous than we could handle, our appearances were apparently perceived as quite worthwhile.

The structure of the chorus was developed so that every person involved is a "key" and valued participant. The group decides the working of the chorus and maintains control. Therefore, every person in the group has equal input.

Transportation has become our biggest cost. Other costs were material for our red vests and flowers (which the senior center director made); sheet music; and an occasional party treat for the group celebrations. Staff time was either on a voluntary basis, or staff-shared from other programs. The Senior Companion volunteers are funded through the state developmental disabilities agency and were "borrowed" from their regular placement sites.

Lessons Learned

Many and varied governing regulations tend to be a major si umbling block

For example, due to the state developmental disabilities agency's regulation on medication administration, if a chorus member needed medication, a medically certified staff person would have to go to the location to administer it. Normalization is more difficult to achieve this way.

Likewise, communication was at times an issue due to the number of agencies involved and the frequency of performances. Coordination between so many facilities and differing systems required much time and organization.

Transportation is a concern, as it is for most community efforts

The OCARC Transportation Department provided all the transportation for the chorus, except for one trip for which the city of Utica's Senior Bureau provided a bus.

A project leader is crucial

Probably the single most important ingredient is to have one person willing to take the lead who sees this goal as a worthwhile effort no matter what the barriers. That sense of vision is crucia! The facilitator can be from any network but must "own" the chorus and continue to persevere toward its success. Problems are brought to the chorus members and resolved through their suggestions. For example, once when there was an unexpected problem with transportation, the members "car pooled".

Problems can be resolved through networking on the administrative level.

Much of the networking can be done by telephone calls, but some structured meetings are also helpful. As mentioned, the Oneida County Aging and Mental Retardation and Developmental Disabilities Coalition oversaw the chorus and other integration efforts in our locality. In addition, media coverage can help give a project an identity in the community. Performances led to increased visibility and more requests to sing. Logistics, such as needing a piano, were resolved through the contribution of a portable keyboard.

Parting Comments

The chorus has become a collective effort. Each participant works towards the common goal of enjoying each others' company while singing together. Music is a wonderful medium for this goal as it "energizes and organizes." Performing arts, such as a chorus, are ideally suited from two vital aspects -- actual integration of participating members and outwardly, as a communication, public relations medium to the community.

These types of efforts are relatively low-cost, very enjoyable, and a very well-received way to meet the goal of community integration for elderly persons with mental retardation and other developmental disabilities. It's a plus for all involved and the community benefits.



Community Garden Program

Betty Dubiel-Turgeon¹

Case Abstract: This case study describes the experience of a disability agency in rural Connecticut with implementing a pull-out project that involved seniors with developmental disabilities in community gardening. The program took advantage of a public vegetable garden and using the gardening activities exposed a group of seniors to other gardeners. It was found that the gardening experience was a very productive and a useful means of involving seniors with developmental disabilities in community activities.

Introduction

Goodwill Industries of the Springfield/Hartford Area, Inc. is one of the oldest and most well-established rehabilitation facilities in New England. Established in 1925, its mission is to provide comprehensive rehabilitative programming for individuals with special concerns. The driving force behind this renowned organization has been the provision of services to meet the needs of the ever-changing community and divergent clientele. Among the needed services has been a retirement program for adults over the age of 55 with mental retardation.

The Opportunities for Older Adults Program (COA; funded through a grant from the Connecticut State Department of Mental Retardation) was implemented in 1986 and currently serves 42 individuals. The goal of the OOA Program is to encourage growth in the areas of community integration, awareness of self and others and redirected work and leisure activities. Services which have been provided to accomplish this goal include: occupational therapy activities, community outings, recreational activities, reality orientation groups, self-help skills training, behavior management therapy and opportunities for volunteer assignments. The Opportunities for the Older Adults Program strives to build upon the experiences of the individuals it serves and to enable expressed interests and talents in order to create new recreational opportunities for the program.

Two years ago, a handful of program participants became involved in a small in-house gardening project. Soon these individuals were reminiscing about gardening experiences they had while growing up. The OOA staff also no-

ticed how tending to growing plants had an engaging, yet soothing effect on these individuals and how this particular activity brought people together in a socially interactive group.

The seed had thus been planted and soon the idea of an OOA outdoor gardening project was in full bloom.

Project Description

The Opportunities for Older Adults Program is located in the suburban town of Wethersfield, Connecticut. Contact with the Town Hall revealed that the program site was located within a one mile radius of the site of the Wethersfield Community Garden. The Community Garden offers the residents of Wethersfield the opportunity to plan a garden of their own if raising vegetables, flowers or fruits on their own property is impossible.

The OOA staff felt that the prospect of participating in a community garden was realistic and advantageous for several reasons. Not only would this type of experience foster integration with the community at large but it would also encourage physical exercise and movement, outdoor activity and the satisfaction of seeing a project through from the planning and planting phases to the harvesting phase.

Under the direction and supervision of four full-time staff members, a core group of three program participants began planning for the garden. The first hurdle to be cleared was securing the piece of land to be used. There was some initial hesitance on the part of the town to let the program use a plot of land in the com-



Correspondence should be addressed to: Betty Dubiel-Turgeon, Program Director, Opportunities for Older Adulu, Goodwill Industries, 370 Silas Deane Highway, Wethersfield, CT 06109.

munity garden. Much of this hesitance was grounded in a general lack of knowledge about our program participants. Through much informal education and hard work by program staff this barrier began to crumble. Following the guidelines established by the town, the program used one of our seniors who resided in the town of Wethersfield to sign up for the use of the garden plot -- thus enabling all the others to use it. This task was accomplished and the planning proceeded.

The gardening project actually starts each February with a meeting to discuss the items to be planted and harvested in the garden for the upcoming season. These meetings are supervised by one staff member and usually involve two to six program participants. At these meetings individuals discuss what they would like to see raised in the garden. All are encouraged to make suggestions and weigh the merit of these suggestions by keeping in mind the size and nature of the plot, the available funds and equipment, the amount of work we can reasonably expect to accomplish and the preferences regarding what vegetables and herbs to harvest.

Once these decisions have been made, we make trips to local supply stores to purchase the necessary equipment. Staff members and program participants select hoes, rakes, shovels, plastic sheets, fertilizer, garden hoses, posts, labels, watering cans, twine and any other necessary items. In addition, seeds and bulbs are purchased in order to begin the planting process.

In late February or early March, when it is still too cold outside, our gardeners begin planting the seeds and bulbs in our greenhouse area. These tiny plants are the foundation of the garden. Any interested program participant may choose to participate in these planting groups. Educational discussions about the plants and our garden are promoted by the supervising staff member.

Generally, the OOA staff and program participants begin visiting the garden site in mid-April after the town has plowed the area. Plans begin in earnest for deciding what plants will be located in a particular area of the plot and in early May transplanting the seedlings from the center to the garden begins. Throughout the summer months, a variety of herbs, flowers, vegetables and fruits are nurtured and harvested.

One of the more practical aspects of this project has been the opportunity afforded our seniors to interact and socialize with other users of the town's community garden plot. Many of the garden neighbors have stopped by to say "hello," get to know us, and exchange gardening tips. As the OOA program participants tended the garden they not only interacted with community members, but they were able to bask in the glow of a job well done.

The seniors also coordinate activities related to the harvest and sale of the produce that was raised. Volunteers from the program are needed to wash, weigh, bag and label all items collected from the garden. The seniors must also determine the amount of money they should charge for the vegetables, herbs, fruits and flowers they intend to sell. This research may involve taking trips to local grocery stores and review of newspaper flyers to determine fair pricing of the items. These activities work to foster community integration and socialization.

Produce is not only sold to friends, program staff, community members and other Goodwill staff, but it is also used in other projects at the program site. For example, herbs may be used in a cooking group addressing good nutrition or fruits may be used to demonstrate canning or jam making.

The cost of the garden project has varied from year to year with a consistent decrease in the amount of financial resources necessary to support the program. When we started, we had \$200 available for start-up costs. Actual expenses included: \$20 for the garden plot, \$100 for equipment and \$40 for seeds, seedlings and bulbs. Each year we find ourselves requiring less money for equipment with more income being generated from produce sales. This financial security has enabled us to expand the variety and number of items we plant and harvest.



All revenue used in this program is subsidized by an annual grant through the Coanecticut State Department of Mental Retardation. Ancillary support is generated through produce sales.

Lessons Learned

The OOA Community Garden Project, currently going into its third year, has not gone on without obstacles. Consistent with any new program, one must often adopt a "live and learn" attitude and tackle one problem at a time. Some of our lessons learned include:

Pick a task that can be undertaken by the people in your program and make sure it is one that will be fun and rewarding for them.

Gardening can be hard work. An obstacle has been the very physical nature of maintaining a garden. The lifting, bending and hauling tasks involved with a project such as this one can be particularly difficult for older persons. Becoming aware of the need to schedule relatively short gardening periods (three times per week for no more than one hour) is key.

Also helpful: alert staff to look for signs of fatigue and boredom and avoid haste in any project associated with the garden. Dehydration is also a concern, primarily in the outdoor activities. Plenty of water in jugs is a must. In addition, varying the individuals involved with each activity avoids burn out and provides new blood to the project.

Activity supports need to be well thought out and it is helpful to have a staff member with a personal interest in the activity.

Another obstacle encountered was the logistics of the garden plot itself. The lack of paved or bricked areas reduce the accessibility of the plot and render it wheelchair inaccessible. This problem restricts people who use wheelchairs for their mobility needs from actually working the garden. To date, these individuals have been involved in the garden project through indoor activities such as planning, planting seedlings, harvesting and selving. These individuals also visit the garden regular-

ly to check on progress and to interact with the other community garden plot owners.

We remain hopeful that, through continued community education and visibility, we will be able to have a positive impact on the Wethersfield Town Hall and to increase the town workers awareness of problems with accessibility and disabilities in general.

Another problem we encountered was the lack of adequate gardening equipment. The staff generously lent their own equipment which supplemented a rather thin budget for the first year. The problem of adequate equipment has declined steadily each year. This decline has been due to the addition of several new pieces of equipment. The equipment was purchased from funds that we raised by selling the produce which we harvested at the garden.

An additional barrier has been the lack of restroom facilities at the garden site. Returning the entire gardening group to the program site for sporadic use of the bathroom was cumbersome and difficult at best. The addition of a vehicle and another staff member to accompany the garden group appears to have rectified this situation. Now, one staff member and several gardeners may remain on site while the additional staff member in another vehicle returns to the program area with the person in need of the bathroom. This easy task is made possible in part due to the close proximity of the garden to the program site.

Make sure you know all about the type of project you will be undertaking

A somewhat less serious problem, and one which offered spontaneous comic relief from all the hard work, was the difficulty on the part of program participants in distinguishing plants from weeds. The task of weeding was, for a time, a hair raising and heart breaking experience for staff. Resolving this problem became one of education and identification of individuals who attained the skill of "weed selection."

Parting Comments

Although it is easier to focus on the obstacles



or problems in any program it is often of greater benefit to examine the successes or benefits gained from a new experience.

The OOA Community Garden Project has had several successes. One is of program participants' growth. Through their involvement with this project, the individuals we serve have regained a skill long forgotten, or have been afforded the opportunity to develop new skills. In addition, OOA staff have noticed an improved ability to communicate on the part of project participants as well as the addition of several new words associated with gardening to their available vocabulary. Program participants have also increased their awareness of the environment and their impact on living organisms. Occupational therapy skills such as spatial ability and number concepts have also improved. The physical, mental and emotional health of our gardeners has improved tremendously through the physical activity this type of project demands. Perhaps most impressive is how the community garden has fostered the development of talents and creativity and has sparked an interest in the future for our consumers.

In addition to the these areas of growth, the socialization aspects of this project have also been of great benefit. Working toward a common goal has fostered responsibility, cooperation and a respect for the rights and ideas of others within the gardening group. Socialization and visibility within the community have also increased with friendships being formed between our program participants and other community gardeners.

The cost-benefit issues associated with this project are strongly positive and financially viable for rehabilitation facilities of every size. For an initial start-up cost of slightly over \$150 (not including staffing and transportation which are generally covered in existing grants), the benefit derived by staff, program participants and the community at large is tremendous.

The development of skills and growth in a variety of areas for program participants has been great. The benefit for staff of having an opportunity to develop and implement a successful and growing program has afforded them an opportunity to develop new skills as well as to become more cognizant of the skills and aptitudes of our consumers. The agency too has benefitted from increased community visibility in terms of public relations and marketing and the surrounding community has benefitted from the interaction with our program participants.

To continue to provide the highest quality services available, the Goodwill staff constantly strives to improve its programming. Within the Community Garden Project, three areas of potential improvement have been noted: the accessibility to the garden plot, the allocation of staff time to the project and the involvement of community members with the OOA Program.

We are working to secure a garden plot that is wheelchair accessible. In addition to continuing to work with the town of Wethersfield to improve access to garden plots, we are seeking to build and use raised gardening beds to be used by persons in wheelchair.

The Community Garden Project greatly underestimated the initial time and effort needed by our staff to create such a program. The physical labor, exacting planning, and weekend work require a truly dedicated and somewhat knowledgeable staff. Each year, the gardening becomes easier and more enjoyable for both staff and the seniors; however, the initial set-up effort involved should not be taken lightly.

We are seeking to increase the number of community residents who are involved with the garden project in order to enhance their integration. Initial plans include utilizing those area senior citizens who have initiated contact at the community garden site to volunteer with the OOA program and share their gardening, cooking, baking or canning expertise.

For those providers who wish to experience the joys of a gardening program here are some guidelines to assist you in the start-up phase:

Spend a significant amount of time planning all aspects of the program (from purchasing the seeds to storage of the goods harvested).



- Provide activities that are both active and passive as well as indoor and outdoor to enable as many people as possible to work on the project.
- Start off with a workable number of interested participants and a reasonably sized garden, then grow at a rate that is supported by available staff time and financial resources.
- Make use of all available community resources (such as, libraries, films, nurseries and garden experts) in your area and help program participants to contribute their ideas, knowledge and skills in all phases of development and implementation of the garden.
- · Be prepared for situations that may be out of

your control (for example, weather or insect pest problems).

The Opportunities for Older Adults' Community Garden Project has far surpassed our initial expectations. We recognize the program's ability to offer ongoing opportunities to foster personal growth for all individuals involved with the project. The teamwork involved in planning, planting, canning, harvesting, cooking and selling fresh produce to friends and neighbors has provided memorable and enjoyable times for all. More importantly we have become a part of the community, using and sharing a town resource and making new friends. We look forward, with enthusiasm, to the continued growth and expansion of this valuable project.

LIVE Senior Services

Sandra Boudreau¹

Case Abstract: This case study describes two projects in the Placer County, California area. The agency attempted to set up a number of opportunities for seniors from their agency to interact and share activities with seniors from the community. It was found that degree of integration and involvement with other seniors was highly dependent upon the type of community and the nature of the other seniors who make up the membership of the community's senior center.

Introduction

Placer County ARC's Senior Services' concept began when the growing population of seniors being served in an activity center did not want (nor did it seem appropriate for them) to participate in job readiness training. They wanted a quieter, calmer group activity, more suited to their age and stamina.

The original group of 15 -- which was considered at the time the grant was written -- grew to 32 by the time the funding was appropriated. Currently, there are thirty-six seniors with devel-

opmental disabilities being served in two locations. We call our seniors program LIVE for "Lessons in Vitality for the Elderly."

Project Description

The senior services were designed to serve people with developmental disabilities aged 55 and over. The program hours were set from 9:00 a.m. to 2:00 p.m. -- a reduction from typical day programs. Our previous experiences with this population's stamina and attention span had shown that a reduced day would be better



Correspondence should be addressed to Sandra Boudreau, Placer County ARC, 151 N. Sunrise Avenue, Suite 1002, Roseville, CA 95661.

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for them.

The start up grant came from Program Development Funds from the State of California, Department of Developmental Services. The funds from the grant were to be used to serve the catchment area of Placer County and parts of bordering Sacramento County -- a predominantly rural area. Although the original senior program began in a small community of Rocklin, we also began a program in Lincoln. As our agency has served the entire county, these central locations were chosen in order to minimize the time needed for the seniors to be transported from their homes to senior program sites.

Interestingly, we had quite different experiences in the two sites we used. In our naive anticipation of being able to use available senior services freely, we planned the daily schedule toward integration as much as possible. At Rocklin's senior activities program -- a nutrition site -- we found that not only were our seniors not accepted by the majority of other seniors, but the activities were geared to a much faster pace than they could keep. We also found that many of the seniors were not too social with one another. Whether this was an ideal situation for integrating anyone was called into question. However, Rocklin was a place where many seniors lived and although it has some liabilities (no sidewalks or busses) we wanted the seniors to have a program that was rewarding and available for them.

For our second experience, we decided to locate a program site that we ourselves would operate as a senior program. We found a house in Rocklin that was accessible. The builder designed the house with "front control" appliances: extra wide doors, adaptive hardware on the doors and a wheelchair ramp. Because we wanted our seniors to build friendships beyond those of us who are paid to be with them we decided to build a "buddy system" into our program by "reverse mainstreaming." We received a grant from the local arts council to hire a staff person who taught classes at our senior site which were open to anyone in the community.

This effort was somewhat successful for the

duration of the grant. Two women who participated in the project have continued to conduct a sing-along every Friday. Unfortunately, most of the one-on-one friendships still did not develop.

In order to pursue the idea of having friendships form among their aging peers in the community, we received another grant from the Sierra Foundation to set up "Adopt a Friend" for a special outing such as going to a movie, lunch or art gallery where we would pay the volunteer's expenses and reimburse him/her for his/her mileage. We approached all the senior groups and churches as well as advertised in local newspapers for volunteers. Again, we had no success and thus, we were forced to return the grant money.

"... we had quite different experiences in the two sites we used. In our naive anticipation of being able to use available senior services freely, we planned the daily schedule toward integration as much as possible. At [one] senior activities program -- a nutrition site -- we found that not only were our seniors not accepted by the majority of other seniors. but the activities were geared to a much faster pace than they could keep. We also found that many of the seniors were not too social with one another. Whether this was an ideal situation for integrating anyone was called into question..."

At that point, we already had a successful, active seniors group participating in activities of their choice on a daily basis, and integrating with other seniors when possible. Unfortunately, many elderly people were openly cruel and verbally abusive. Therefore, we have had to be



careful not to subject our seniors to such treatment.

Within the past calendar year, we opened a second senior service in the small community of Lincoln. This program -- which served a small number of seniors -- is totally integrated within a recreation center in the heart of the town and within walking distance to stores, the senior nutrition site and restaurants. We serve only 12 seniors with two staff. The seniors can check out a video, purchase a craft project, have lunch out with a friend or get their hair done within just a few blocks of the facility.

Another opportunity for activities is to attend art classes at a facility where the ARC has rented space. The esteem building has been phenomenal and the quality of the work being turned out is terrific. The seniors at our Lincoln site are involved in a number of enjoyable activities, including participating in a kitchen sink band (we supply the music teacher). Many help out at the nutrition site by serving lunch.

Our catchment area is very rural and large. We have attempted to set up programs near the seniors to cut down on the "drive time" necessary to get to the programs. Like other seniors, our seniors found that communities differ markedly, some are friendly and accommodating and some are cold and rejecting.

We had two different experiences. In one, the other seniors were not very friendly and we went off and developed our own program site, inviting those who cared to come to join us. Not many came, but we made good use of the community just as well.

In our other site, we had a good experience. Our seniors fit right in and became part of the on-going activities. Sometimes you lose, sometimes you win.

Lessons Learned

A physically accessible service site is of great importance to integration.

With luck, we located a house that is accessible. This lesson was a valuable one as retrofitting existing structures is extremely expensive. Other facilities we have needed since then have been "built-to-suit" prior to lease.

A complete community inventory for accessibility must be done prior to leasing any facility.

Sensitivity to disabilities which are common to all seniors (e.g., hearing loss and arthritis) must be kept in mind. For example, if your agency is located within two blocks from the main business section, but there are no sidewalks, traffic lights, or other safety improvements, this location is probably not a good one. If the facility is on a steep incline, or has lots of stairs, it is probably not suited for the elderly population.

Very small groups, gradually introduced into various activities work well.

Even though staff may support the integration of people with developmental disabilities, the public may not mean be ready to do so. Volunteering to help out in various community services works well in building some friendships.

Parting Comments

Do not give up. Take the time to establish relationships with fellow administrators and use every opportunity to educate staff from other agencies and their service recipients. It may be necessary to try every avenue. Look for common interests among the seniors who have disabilities and those who do not and make one-on-one connections whenever possible.



Project Together

Mary E.T. Grassi and Charlotte B. Parkinson¹

Case Abstract: This case study describes a special program in Brooklyn, New York that sought to provide shared socialization experiences for two groups of seniors: one from a developmental disabilities seniors program and the other from a local senior housing program. The objective of this program was to offer shared experiences that would bring the seniors together. It was found that such a program effort can be effective, but not without expense to the agency -- it did however, prove to offer fellowship and an opportunity to break down some psychological barriers.

Introduction

The purpose of Project Together is to implement the concept of psycho-social integration for two groups of people: elderly individuals with a mental retardation and age peers who are members of local senior centers. The program is based on the assumption that all senior citizens, regardless of their level of functioning, can enjoy retirement activities together.

Project Together, jointly funded by the New York State Developmental Disabilities Planning Council and Builders for the Family and Youth, Diocese of Brooklyn, Inc. (BFFY) is an effort to bring together senior citizens with developmental disabilities and other senior citizens for the purpose of enjoying a variety of retirement activities. Four times a month, seniors with mental retardation and other seniors are offered the opportunity to meet and enjoy a planned activity.

The project is located in Brooklyn, New York — one of the five boroughs of New York City. BFFY is one of the major providers of social services within the borough and offers a number of family, senior and disability related programs within the borough.

Brooklyn is the largest of New York City's boroughs. Its ethnic and culturally diverse population of some 2.3 million persons is spread over a large number of neighborhoods, many made up of new immigrant or old settled groups. The Catholic Diocese's social agencies provide services to a diverse population within Brooklyn not restricting its services solely to

one religious group. It has a large older population of long time residents.

Project Description

The design of Project Together is based on concepts which had been successful in another BFFY program: Senior FUN. In 1989, Senior FUN (Fulfilling Unmet Needs) was set up to meet the needs of elderly senior citizens with mental retardation who had in one way or another demonstrated that they might enjoy retirement activities in lieu of attending their highly regulated day programs. Since the start of the program, seniors with mental retardation who were in day programs and those who had never been in a day program have also been accepted into the program. The program served twelve people who had mental retardation in the mild to severe range who were between the ages of 60 and 75. People attending Senior FUN were able to choose from among a range of activities which were enjoyable, relaxing and suitable for their age group.

The program was housed on the first floor of a neighborhood senior citizens housing building. This location led to a spontaneous and informal relationship between the program participants and the older people who lived in the building, and allowed them to learn about persons with mental retardation in a non-threatening way. The seniors in the building were asked to join the seniors with mental retardation for scheduled activities including sing-alongs, theme parties, and picnics.



Correspondence should be addressed to Mary E.T. Grassi, M.Ed., Program Specialist, Office for Disabled Persons, Brooklyn Catholic Charities, 191 Joralemon Street, Brooklyn, NY 11201 or Charlotte B. Parkinson, D.S.W., Program Specialist, Office for the Aging, Brooklyn Catholic Charities, 191 Joralemon Street, Brooklyn, NY 11201.

We learned a lot from the staff and people who attended Senior FUN. This information was used to develop Project Together. Senior FUN explored choices of activities which would be of mutual interest. Project Together took the concept of mutually enjoyable activities and built on that idea. Community trips are a large part of Project Together's way of offering mutually enjoyable activities. Site-based theme parties are also a part of this program.

Project Together started in November 1990 and by May 1991 over 60 seniors from the senior housing program and 30 seniors with mental retardation had become involved to some extent in our program. Because Senior FUN had successfully served people with mild to severe mental retardation, Project Together chose to serve seniors in those same ranges of intelligence.

Project Together has an ideal location, being situated in the same building as Senior FUN. The director of Senior FUN served as a consultant to the program and has been involved in all stages of its development. Drawing on Senior FUN's successes and learning from failures greatly assisted Project Together's smooth running. Further, because BFFY is a large agency with a sizable aging office, there has been both support and information sharing on aging-related issues which has benefitted the program. In short, the Senior FUN experience provided a strong and solid base for Project Together's operation while the Office for the Aging's ongoing involvement and encouragement bolstered the movement of the program towards the participants' psycho-social integration.

Project Together has sponsored a variety of opportunities for interaction between the two populations. The format was simple. The program coordinator identified different types of experiences which may have provided both enjoyment and enrichment to the two targeted populations. She then identified people who may have had an interest in joining the scheduled activity and offered them invitations. A selective assessment of attitudes was often done so that seniors who would not have been good social partners were screened out. Next, she

arranged for all aspects of the event.

For example, recently Project Together offered the opportunity for people to come to the site and enjoy the entertainment of a senior center's glee club. The program was followed by a luncheon. Using the simple idea that everyone enjoys food, music and conversation, this event was a success. Further, it provided for an enriching opportunity for the glee club members to be with people whom they might not have had the opportunity to meet if the event had not been presented.

Another activity included a Valentine's Day theme party. The seniors who lived in the senior housing program were engaged by the program coordinator in conversation about mental retardation while they assisted with the preparty planning and decorating. These seniors then served as hosts at the party to the other seniors. On another day, about seven of the seniors enjoyed a luncheon cruise around New York Harbor. Project Together funds paid for the refreshments. Everyone joined together on the dance floor after lunch and had a good time dancing.

These experiences encouraged reciprocal interaction and sharing, and provided the opportunity for life enhancement to all the seniors whether they had mental retardation or not. These activities, however, were carefully orchestrated so that a maximum amount of interaction could occur during these "real life experiences." Further, the availability of some grant money enabled everyone involved to enjoy an activity without having to worry about transportation headaches or the high cost of such events in marvelous New York City.

These events, of course, were not without some problems. One of the problems encountered was the varying level of acceptance of people with mental retardation by the general public -- in this case other seniors. However, in most instances, we did not run into a major problems with a lack of acceptance. We wondered whether or not socio-economic differences created a commonality which may have accounted for the lack of awareness of this barrier.

Lessons Learned

The high cost of living in the New York City area is a major problem to integration.

Private transportation in the New York City area is very costly. The Project Together grant did not have sufficient money to provide for all the transportation that was deemed necessary for the optimum opportunities for recreational enjoyment. However, an advantage that we had was the possibility of using BFFY agency vehicles when they were not in use during the time Project Together trips were scheduled. We also found that, in most instances, another staff person on each outing would have been a helpful addition in order to ease maximum interaction between all the participants. In some instances we could call on our friends in other BFFY programs for help, but this did not always work.

Having a host agency that can absorb some of the project expenses and provide other assistance is an asset.

Our host agency took a great deal of responsibility to go above and beyond the required expected "cost share" of this program. Available expertise in the field of mental retardation and in the field of aging has meant that hours of research in each field was not necessary. Further, if an extra worker was needed for a trip, the agency has a list of people who have experience with taking consumers out into the community. Finally, the acceptance of people with mental retardation by the aging world has been shown by many agencies to be a long, hard road to travel. Because the host agency sponsors many aging programs already, there were "friends" to approach with the idea of integration. For these reasons, it may be difficult for a smaller agency or an agency which serves only the aging or only persons with mental retardation to reproduce this type of program.

Parting Comments

This program started with a specific group of people with mental retardation in mind. Because the host agency had a large department which provided a variety of services to people with mental retardation and their families, we knew that we would be able to meet the goal of serving 30 seniors with mental retardation and 30 other seniors. Further, because of the success of the Senior FUN program, this was a natural "next step" in learning about seniors with mental retardation -- how best to facilitate integration, and how to take the idea of integration one step further by trying to invite people without a developmental disability into the developmental disabilities world. Support from the BFFY's Office for the Aging and BFFY's Office for Disabled Persons have been a great benefit. Being able to draw from experts in the field and not having to do extensive research in either area facilitated a smooth easy start to this program.

Project Together was a small program in a very large city. Small seems to work best for this type of integration. It is not normal for large groups of people with mental retardation to go on a trip together, nor is it realistic to expect that there will be the opportunity for positive interaction with each other or a positive reaction to the stimuli presented. Project Together offered the opportunity for a few individuals with mental retardation to join together with others and explore all that New York City has to offer.

Projects like Project Together can be a stepping stone to full psycho-social integration of elderly persons in the community. These programs are dedicated to making opportunities visible to persons who are both old and have developmental disabilities and because of either condition are considered disposable and have been "put away." We imagined something better for them. We also felt that Project Together could be helpful to young people, especially those who have a disability. They could see how elderly persons with a disability could adapt to old age and to the opportunities provided by Project Together of similar programs. Project Together demonstrated that older persons with a developmental disability can manage, can enjoy themselves, and can participate in community activities.



With age our needs and interests change. Where independence and competitiveness may have been the watch words for young adulthood and middle age, the prevalent attitude in late adulthood is interdependence. This latter stage of life is more conducive to working and being reliant upon others and looking forwards to the rewards of social interactions and friendships. This is true too among many older persons with developmental disabilities as they begin to phase out of vocational programs and seek out options within retirement.

We observed a number of the situations which used the model of the senior friend -- or companion -- to help someone, who relied upon the disability system throughout his/her life, begin navigating the unchartered waters of the aging network. Such companion models worked because they offered both role models for later age and a friend to help broker, heretofore, unexperienced situations. These models ranged from programs where a retirement coach was used to help guide the transition to senior services to situations where seniors were paired because they wanted to mentor and then share some collective experiences. We also saw the creative use of the federal Senior Companion program, where senior volunteers helped in situations that promoted greater use and enjoyment of available senior activity programs.

The lessons learned? Probably the foremost was that one cannot assume an older person will automatically make use of his/her retirement and that programs which helped to explore the use of available options proved helpful. Volunteer-based programs are not easy to operate and involve a great deal of pre-planning and support. Senior companion programs are often more normative because they work on a one-on-one foundation and provide a more meaningful basis for assimilation.

ompanion Venture

Community Based Support Systems Program

Lisa M. Turner & Theodore Bryant¹

Case Abstract: This case study describes a small, one-on-one retirement program operated by a contractor specializing in providing community-based recreational services in Seattle, Washington. The user-fee-based program provides individualized leisure time activities and community involvement with the help of volunteers and a certified recreational therapist. The project has served as a model to help stimulate the development of new programs for seniors with developmental disabilities.

Introduction

In the early 1980s, the Washington State Division of Developmental Disabilities expressed in its official state plan the need for preretirement and retirement services for older adults with developmental disabilities.

In response to that stated need, the Community Based Support Systems Program was developed as a pilot project in 1983. At that time, few retirement programs existed for older adults with developmental disabilities in the United States. Furthermore, community-based retirement programs using a non-facility based approach were nearly non-existent. The Community Based Support Systems Program (CBSS) pilot project filled this vacuum by combining a non-facility based approach with an intergenerational volunteer companion model.

By using a variety of existing community resources and facilities (recreation centers, bingo parlors and movie theaters) in combination with the recruitment of non-disabled adult volunteers of all ages, the CBSS program established a unique approach to service delivery in Seattle, Washington.

Today, because of this innovative program design, the Community Based Support Systems Program (CBSS) has become a model program that continues to be funded by the King County Board for Developmental Disabilities.

Seattle, a large city of some 516,000 population, is the core a large metropolitan area in northwestern Washington state.

Program Description

The Community Based Support Systems Program was developed in 1983 by Lisa Turner, a certified gerontologist and recreational therapist, with input from professionals in other fields who provided an interdisciplinary perspective. The program was designed to promote involvement in community-based leisure activities for older persons with developmental disabilities. The program focuses on leisure skills development, retirement preparation, personal independence, life enrichment, community integration, and the use of existing community resources and facilities.

The program works like this:

- Step 1 -- CBSS recruits non-disabled adults from all age groups from the greater Seattle area to become volunteer companions.
- Step 2 -- once accepted into the program, each volunteer receives training and ongoing supervision.
- Step 3 -- the volunteer is then matched with an older adult who has a developmental disability and similar leisure interests (leisure interest rather than age determine how matches are made).
- Step 4 -- the volunteer companion takes the older adult who has a developmental disability into the community once a week for an activity such as be a movie, a visit to a senior center, a walk in the park, or maybe something as simple as a cup of coffee at a nearby restaurant.



Correspondence should be addressed to Lisa M. Turner, M.S. or Theodore Bryant, M.S.W., Community Based Support Systems Program, 5127 Twenty-fourth Avenue, Seattle, WA 98105.

The shared leisure activity creates a bond between the two people. Ideally, these relationships are long lasting.

The objectives of the Community Based Support Systems Program are to provide older persons with developmental disabilities access to retirement and leisure activities that are designed to: increase participation in the community at large, encourage integration with non-disabled persons, emphasize individual leisure interests and preferences, and aid in the preparation for and/or enjoyment of the retirement years.

Over the last nine years, the program has seen numerous older adults pass through and become involved in a range of activities. The adults have ranged in skill level, age and abilities. For example, of the 19 participants currently being served, all but one have been institutionalized for some period of time. Seven participants still reside in a state institution, one participant resides in a nursing home, the remaining eleven participants live in community residential settings or semi-independently in the community. The age range of program participants is 57 to 85 years. The oldest participant, who was born in 1906, has spent over 60 years of his life in institutional settings.

None of the program participants has ever married, and now because of their advanced age, most of their parents, as well as many of their siblings, have died. In other words, the CBSS Program participants have little, if any, family support system left.

The individual mental levels of program participants vary greatly. The majority of CBSS participants have mental retardation as their primary disability. Visual impairment and cerebral palsy are the primary disabilities of three other participants. Severe behavior problems of potential participants, which might overwhelm non-professional volunteer companions, are considered by state Division of Developmental Disabilities case managers before referral to the program. This program, however, does provide services to participants regardless of their level of mental disability.

Physical disabilities, however, pose a greater problem for this program because the program is a volunteer program and individual volunteer's private transportation is used. Consequently, we have found that it is unrealistic to ask a volunteer to provide heavy physical assistance to participants, such as lifting participants from wheelchairs to cars. Therefore, all program participants must be able to transfer in and out of automobiles without extensive assistance.

Participation in the CBSS program is voluntary. All potential participants are referred to the program by their case managers. In an initial meeting between the potential participant and the program director, participants are provided with a Consumer Handbook. This information is read to the potential participant by the program director. The information must be read to participants because most older program participants are unable to read (because special education services were not available when they were younger).

Upon acceptance into the program, the participant completes the Leisure Preference Questionnaire and the volunteer completes the Volunteer Companion Interest Questionnaire. The program director then uses the two questionnaires to develop a formal leisure plan for the participant.

People from the general population, as well as graduate and undergraduate students, are recruited as volunteers. The recruitment of volunteers is accomplished by sending Public Service Announcements (PSAs) to the media in the greater Seattle area. The program director also talks to service groups and university classes in order to recruit volunteers from these segments of the community.

During 1990, a total of 2432 hours of direct service time was provided by volunteer companions. Without this ongoing volunteer assistance, the Community Based Support Systems Program would not be possible.

After careful screening, all volunteers receive specialized training and ongoing supervision. Volunteer training sessions include the following



topics: CBSS program guidelines, goals of CBSS program, volunteer and consumer rights and responsibilities, developmental disabilities, beginning and terminating consumer relationships, communication skills, community leisure activity ideas, and "luxury leisure for less."

The Community Support Systems Program continues to be funded on a fee-for-service basis by the King County Board for Developmental Disabilities. The program director of Turner Associates, donates office space, travel expenses, utilities, and telephone fees. These in-kind donations are based upon the belief that a social service program cannot ask others (volunteers and community groups) to give their time or money unless the program staff does the same. The only paid staff position assigned to the program is that of the program's director.

Because the CBSS program is funded on a fee-for-service basis, the revenue base fluctuates as the participant base changes. Program costs such as insurance, professional services, and office supplies remain constant.

Lessons Learned

The addition of a part-time staff person who would assist and temporarily replace volunteer companions when needed, would provide an additional dimension to the program.

Having a staff person assist the volunteer companions, who are matched with participants who have more severe/profound mental retardation, would help retain volunteers for a longer period of time. It would also reduce the burnout factor which occurs while working with persons who do not or cannot provide positive responses to their volunteer companions.

☐ It takes a lot of time and patience to coordinate a volunteer program.

The rewards are great when it works. Time is needed for community integration to work and there are degrees of integration. For example, the seven participants who still live at a state school may never achieve full community

integration in terms of independently maintaining friendships with non-disabled persons who reside in the surrounding community. However, with the assistance of a volunteer companion these same people can participate in many of the same community-based leisure activities in which all of us participate.

The CBSS program was designed with the expectation that volunteers would provide all of the community outings. However, the program has learned that volunteers come and go. In order to provide continuity when a volunteer suspends service (illness, vacation, etc.) or terminates, the program director donates time as a volunteer companion until a new match is made. This unforeseen occurrence has turned out to be a good development because it allows the director to communicate directly with the participants.

- Oversight of a retirement assistance program can involve a number of facets, some expected, some unexpected.
 - Costs are always more than you plan for -- try to plan for this occurrence.
 - Fee-for service payment makes it difficult for programs to stay small.
 - When running a volunteer program, staff members must be available to fill in for the volunteer whenever the circumstances dictate.
 - Community awareness and involvement is a must in community integration programs. After all, the goal is to connect older adults who have developmental disabilities with other people in their community. So, get to know the community and its resources well. Do not forget that organizations, service clubs, and individuals, are all valuable resources.
 - There are advantages to keeping this type of program small. Individual leisure preferences are not compromised. For example, given a choice, not all participants enjoy going to a senior center for classes or lunch. Smaller, more individualized programs can cater to peoples' leisure interests and



preferences by matching them with volunteer companions who have similar leisure interests. We have found that these mutual interest matches tend to last.

Parting Comments

Recently, several new programs for seniors with developmental disabilities have been established in Washington State. The CBSS program has been instrumental in creating an awareness in this state about the needs of older adults with developmental disabilities. In many instances, the CBSS program is used as a model by other service providers who are starting senior programs for adults with developmental disabilities. The program continues to provide technical assistance and training to agencies interested in developing senior programs.

The CBSS program continues to provide older persons with developmental disabilities access to community-based leisure activities. With the assistance of volunteer companions, the program provides community integration with non-disabled people which helps participants enjoy their retirement years. People continue to be referred to the program. At this time there is a waiting list, however, the program remains small, and consequently is unable to accommodate all the people who request services.

When developing a program which combines the principles of community integration and generic leisure/retirement services, do not be afraid to try new things, explore options, and encourage creative, unique, and individual solutions. Remember that new and interesting leisure options coupled with companionship equals an exciting program. Also remember to start small and grow slowly, and do as much preprogram planning as possible.

Senior Integration Program

Ellen B. Carter

Case Abstract: This case study describes the experiences of a large disability agency in Queens, New York, in helping seniors with developmental disabilities to access neighborhood senior centers. The cornerstone of this program is the active involvement of Senior Companions who accompany the seniors to the centers. These individuals have received special training in working with older people with developmental disabilities. It was found that the success of the program depends on creative planning which includes careful matches between the senior, the senior companion and the geographical location of the senior centers.

Introduction

The purpose of Senior Integration Program (SIP) is to help seniors with developmental disabilities to transition from a sheltering, restricted environment to one which is more ingrained within the community. With creative planning and special advocacy, retirement into community-based centers is a reality. This case

study demonstrates the evolution of a transitional work/recreation program -- GOALS (Growing Older Accessible Life Services) -- to one that aids in the use of senior centers in the community. The tools for implementation of the project include: the Senior Companion Program, trained volunteers and careful selection of candidates for the move.



Correspondence should be addressed to Ellen B. Carter, M.A., Coordinator of SIP and GOALS Program, United Cerebral Palsy of Queens, Inc., 81-15 164th Street, Jamaica, NY 11432.

Three years ago, a recreation program was designed and implemented at United Cerebral Palsy of Queens (UCPQ) in Queens, New York. Queens is one of the five boroughs of New York City with a population of some 1.9 million persons.

The goal of this program was to meet the needs of older persons with developmental disabilities who were aging out of sheltered workshops. The program name GOALS was adopted and its activities were modeled after a community senior center. The actual design for the program came from suggestions made by senior program participants who were attending a weekly rap group and were ready for part-time retirement.

The structure of GOALS included age appropriate health education, social awareness, games, community field trips, shopping and a nutritional hot lunch. Referrals to this unique program for Queens came from in-house program participants attending UCPQ workshops, the Queens district office of the state's developmental disabilities agency, other agencies serving people with developmental disabilities, and community people who heard about our services.

To date, referrals ranged from fully ambulatory individuals with mild mental retardation who were between the ages of 50 and 77 to four mobility impaired individuals with cerebral palsy who used walkers and crutches. The program participants who were at first skeptical of retirement and were attending GOALS only one to two days per week, enjoyed the activities and increased their days of attendance. It was evident that some of the program participants in this group were now ready to move out into the community to be integrated into neighborhood senior centers.

The addition of the SIP Program was conceived with a vision that careful planning with community linkages could move the seniors with special needs into the existing aging network centers. The plan was to match socially appropriate program participants with Senior Companions to neighborhood senior centers.

Geographical matches were also adopted in order to place the service recipients and their companions into an accessible center close to their homes.

Project Description

SIP evolved as a complementary addition to the GOALS program. It was observed that many seniors who had been participating in the "special" senior program (GOALS) were ready to move on to the community senior centers.

The first task in organizing the project was to identify the "players" in the project (i.e., the seniors who were ready for integration, the senior centers located in their neighborhoods, and the vehicle for the move, the senior companion). The Senior Companion Program has specific rules, regulations and guidelines as set down by the state of New York, which funds this group. Their income level cannot be more than \$8,600 per year from Social Security, they must be physically healthy and be able to devote twenty hours per week towards working with individuals with developmental disabilities.

In addition, Senior Companions must receive forty initial hours of training and four hours per month of ongoing training. Attendance records, profile records and goal sheets are kept on each participant. The recruitment for this part of the SIP was lengthy. Also, many retired seniors do not want to commit themselves to twenty hours of work per week.

The work was completed through a media blitz, attending senior citizen programs, advertising in social service departments of hospitals and letters to the clergy. At the same time that the Senior Companions were being recruited, senior centers were being located and appointments with directors were being arranged. The project coordinator and the case workers of the SIP project met with the directors of four centers located near the seniors' homes in the borough of Queens. The centers were visited during activity hours to observe the relationships of the enrollees to each other and to staff, to evaluate the accessibility for the handicapped, and



evaluate the appropriateness of the placement for our participants.

After meeting with the directors to tell them about our program, we in turn invited them to our premises to observe our program participants during activity hours. We also assured them that when our participants attend the senior centers, they will be accompanied by a senior companion and that the GOALS staff will be available for support and guidance. Small numbers of service recipients would be attending once per week.

All the directors were gracious and found our program to be acceptable. The strong support team and the small numbers of participants were the keys to acceptance.

The next step in the process of integration was presenting the "moving on" concept to the participants. Small discussion groups were held, with question and answer periods. It was difficult to get them to think about going to a new place. Change is so difficult for many older people, but older people with developmental disabilities especially feel a lack of security when many new changes in their routine are enforced. We told them the new program was their option, that they could try it and if they did not like it, they would not have to continue.

We prepared them with activities found in senior centers, instilling them with pride in what their community has to offer. The sense of "this is my community," "this is my senior center in my neighborhood," was a concept we developed. The transition was slow and cautious. We established one senior center site at a time.

The Senior Companions were trained at UCPQ to work with service recipients. Their working experience in the GOALS activity program prepared them for moving on to the senior center with their assigned participants. In addition, team meetings, with staff discussing the service recipient's needs, proved helpful as treatment plans and individual goals to be worked on were established.

The following activities in the community were scheduled: attending church services, attending senior centers, helping individuals fill out forms, keeping medical appointments, shopping, going to beauty parlors, visiting parks, going to museums, and experiencing other entertainment, just being a friend and a good listener.

Accomplishments are measured by behavioral observations made not only by the senior, but also by the senior companion. Most of the seniors who reside in the community in foster care or by themselves or with relatives, usually stay home on the weekend and watch television. Since the SIP program began, these program participants are now attending religious services with the Senior Companions as well as other weekend activities. They love being a part of the community and now that they are participating in community activities, they are being accepted as a part of the population. Another contributing factor to their acceptance is the monthly educational seminars on aging and mental retardation which are conducted as part of the SIP program.

Some additional accomplishments from the program include: the exchange of entertainers from the "special" group GOALS to the senior center and vice versa; going to beauty parlors in order to look better groomed; dressing more appropriately when attending senior centers, picking out clothes more carefully; initiating verbalization about forms that need to be filled, thus receiving help from a senior companion; asking for help before a crisis arises; speaking up about health problems before the problems become serious; the encouragement of service participants to get haircuts and look well groomed; filling out forms for individuals with mental retardation who live alone; looking for appropriate dwellings; helping with transportation; and health awareness-medical appointments.

The seniors have found the Senior Companions to be real friends, someone who will guide them, and someone on whom they can rely. The Senior Companions are also enjoying better health and, as they have all said, they now have a reason to get up in the morning. They found



that retirement does not always agree with everyone and this healthy group of volunteers enjoys the sense of helping others. The small stipend they receive, the hot lunch, and the friendship with others, all add up to a greater sense of self-worth.

Some of the barriers encountered in setting up the SIP program included: program participants did not like change and were resistant to moving out to senior centers; senior centers have an age qualification of sixty years old and many of our participants who would like to attend are below that age; seniors companions and participants had special transportation to the UCPQ GOALS Program, but could not get the service to go to a senior center, lunches in the GOALS Program are free but cost money at the senior centers which troubled the participants who do not always have control over their finances; some senior center members were not friendly to our program participants who felt the difference in treatment; some centers have steps which are inaccessible and dangerous to those with ambulatory problems.

These barriers were resolved in the following manner:

- » program participants met in small groups to discuss their fears about change and they were also told that if they did not like the center, it was their option not to attend;
- » transportation problems were worked out through telephone calls, resources available from the community senior centers as well as cooperation from care providers and families;
- » the 60 year age qualification for senior centers is still an unresolved barrier for several individuals with developmental disabilities who are under that age limit;
- » the inaccessibility of some centers was resolved by matching service recipients who have ambulatory problems with centers without steps, while allowing those service recipients who could walk steps to continue attending; and
- » the expense for lunch at the senior centers was resolved through budget preparation for the par-

ticipants who were taught to save \$1.00 from their allowance.

The funding for the SIP project came from several sources. The greater portion of the \$50,000 came from the New York State Developmental Disabilities Planning Council as a grant, in-kind contributions of 30% came from UCPQ, and the remaining funds came from the New York State Senior Companion Program which paid the bi-monthly stipends to the companions. The actual expenditures in the program are as follows: salaries to coordinator, case worker and secretary; monthly seminar series, cost of speakers; refreshments and handouts-printing, transportation for Senior Companions (part of their contract) and one hot meal per day served to the Senior Companions; purchase of program supplies and office supplies; party expenses (birthdays, Senior Companion Recognition Day); transportation to senior centers; conferences, seminars, educating staff.

"The seniors have found the Senior Companions to be real friends, someone who will guide them, and someone on whom they can rely. The Senior Companions are also enjoying better health and, as they have all said, they now have a reason to get up in the morning. They found that retirement does not always agree with everyone and this healthy group of volunteers is enjoying the sense of helping others. The small stipend they receive, the hot lunch, and the friendship with others, all add up to a greater sense of self-worth."

Most of the expenditures that were placed in the original design of the program turned out to be as expected with the exception of transportation costs which were figured on a half fare bus



pass. Many of our Senior Companions are too young for half fare passes. Also, the mileage costs to and from senior centers have been higher than expected.

Lessons Learned

Volunteers may serve more purposes than was initially thought.

Having the SIP program has helped the agency by providing volunteers who work with the older participants. The volunteers have provided additional staffing that would otherwise be unobtainable in light of budgetary restrictions. The older participants who are not able to work any more and who attended these special programs, can still maintain their living arrangements in group homes, foster care and with families. Years ago, when a person "aged out of their program, they were sent to live in nursing homes -- a large expense to the state government.

In addition to the obvious cost-effectiveness of the program, one subtle savings is on medical costs. The service recipients are monitored carefully by the companions and staff, thus reducing the use of emergency rooms. The participants are also taking much better care of themselves and a sense of wellness has been observed.

Networking is an important tool.

Networking with the senior centers and community resources for the aging has enabled the program to utilize and share all the systems. My recommendation for persons wanting to start integration programs is simply tread slowly and cautiously.

This means that senior center directors and staff are overworked and have limited budgets, so that accepting any change in their program which lead to additional staffing and expenditures is threatening to them. Many meetings with the staff, assuring them of support, and small numbers of seniors attending one day per week is a more cautious way of approaching the goal of acceptance. A plan of action firmly in place is also desirable before meeting with the parties.

Plan your agenda before meeting with other agency directors.

Another piece of advice for agencies willing to try an integration project is to locate more senior centers than you need to use in an area. Not all directors of centers are amiable to even a first call. Prepare a brief outline of why the program is beneficial to all aging persons and be prepared to defend your program services.

Parting Comments

The key tools to community integration for seniors with developmental disabilities is creative planning, "special" advocacy and public education. The move must be made with caution, assuring the senior center directors that there will be guidance and a support system, and that all parties will work as a team. The educational seminars help to dispel the myths about developmental disabilities, while visits from the service network in the community to witness the seniors in their "special" setting proved to be valuable in acceptance of the program.

Creative planning for integration includes careful matches between the senior, the senior companion and the geographical location of the senior center. Disbursing individuals to several centers is also better than grouping too many in one center, which can lead to the segregation of groups. It is also improves the inclusion of the seniors in group activities undertaken by other center members. Something shared is also a useful way of "breaking the ice" (for example, one of the seniors enrolled in our program is an accomplished pianist and likes to perform at the senior center — his piano playing has led to more cross-involvement among the seniors).

It is also important to note that not all center directors are interested in this program, and not all service recipients who seem to be appropriate really fit into the "moving out" to the community program. Presenting the plan to all parties must be executed with skill and finesse. It takes time, but the rewards are worth it.



JASA Outreach Project

Robert Goodman1

Case Abstract: This case study describes the activities and barriers encountered by an aging network agency in integrating four of its neighborhood senior centers in Brooklyn, New York. Formal staff training and the use of volunteers were instrumental in facilitating integration. It was found that mainstreaming one person at a time was more effective than group mainstreaming and the use of companion volunteers takes special care, both with training and follow-through by the program.

Introduction

Until recently, people with developmental disabilities had a very short life span: few lived past the age of 50. However, changes in science, medicine, and technology have extended the lives of people with developmental disabilities, so that many individuals with mental retardation have reached "retirement" age.

For many years, people with mental retardation were workers in sheltered workshops or were participants in habilitative day programs. As they "age-out" of their program, these older adults need an alternative to their current program which raises several questions; What will happen to this group? How will they spend their leisure time? Can they take advantage of aging services and continue to be served by the developmental disabilities network?

The Jewish Association for Services for the Agcd (JASA) -- a multifaceted social services agency serving seniors in Brooklyn, New York -- has tried to address these issues. JASA applied and received a multi-year development grant from the New York State Developmental Disabilities Planning Council to operate an outreach effort for older adults with developmental disabilities.

Since September 1990, JASA has sought to identify older adults with developmental disabilities in selected neighborhoods within Brooklyn, assess their needs, and, where feasible, to integrate them into four of JASA's senior centers (Bayview Senior Center, Coney Island Senior Center, Senior Alliance Senior Center, and Starett City Senior Center). JASA's objective was to ascertain whether there was a need and a

role for the aging network to provide services for older people with developmental disabilities. If there was, could a partnership be established between the aging and developmental disabilities networks which would result in better services for the participants who were high functioning.

JASA-Outreach to Developmentally Disabled Older Adults (JASA-ODDOA, as the program became known) was designed to provide older adults (age 55 and over) with developmental disabilities with the opportunities for self-growth, supportive social relationships, and recreational activities. The program sought to identify and assist these older adults in utilizing JASA senior centers as an adjunct to the services they are receiving from agencies which serve people with developmental disabilities. Another objective of the program was to develop a training program to educate JASA's senior center members and staff of as to the needs and capabilities of older adults with developmental disabilities.

Program Description

Older adults considered for JASA-ODDOA had to be able to travel independently or by car service -- a form of taxi -- (unless agencies provided staff and/or transportation), have appropriate social skills and behaviors, have the capacity for appropriate social interactions, enjoy and benefit from being with other people, and be self-medicating and self-toileting. The participants initially attended one of four senior centers on a one day per week basis.

Transportation arrangements were made with



Correspondence should be addressed to Robert Goodman, CSW, JASA Outreach to Developmentally Disabled Older Adults, 3161 Brighton 6th Street, Brooklyn, NY 11235.

two local car services. Except for a few minor start-up difficulties (i.e., car service pick-up scheduling, difficulties regarding handling a wheelchair in the car, and some negative attitudes on the part of some drivers) the transportation system ran smoothly. We tried to use a local paratransit service, but it proved unreliable.

The director coordinated the project and interviewed perspective participants, trained staff and volunteers, acted as a liaison between the developmental disabilities agencies and JASA, and visited the sites on a monthly basis.

"... relationships between the participants and the center members developed slowly. At first, the participants relied on each other for support as they became acclimated to center life. Then, the participants began to make new friends as center members became less fearful of them. ...in one center, where there were many frail and disabled elderly adults, the participants with a developmental disability made friends easily."

Staff of local developmental disabilities agencies accompanied participants two of our sites. Their role was to help the participants get acclimated to center life, assist the participants who were more disabled and act as trouble-shooters as problems arose. When problems did arise, the program director met with the participants, and when necessary, the developmental disabilities agency personnel. Usually the center staff and volunteers were able to resolve difficulties.

Volunteers were recruited formally and informally at two sites. In the beginning, volunteers were assigned to participants on a one-

to-one basis. As the participants were mainstreamed, the volunteers only assisted the participants on an "as needed" basis.

We used volunteers to help the participants become acclimated to center life and the activities. However, we found that volunteers needed continuous support and encouragement from the program staff. The volunteers were encouraged to seek advice from staff when faced with difficult situations. Most of the volunteers acted appropriately, but there were exceptions. For example, at lunch, one volunteer thought a participant was having trouble eating because she was eating so slowly and began to try to feed her. She had to be told to be patient and let the other woman eat at her own speed. We also discouraged the volunteers from doing any heavy lifting or pushing.

The program director, with assistance from developmental disabilities staff participated and developed a training curriculum for senior center staff and volunteers. The first two training sessions included sensitizing people to the needs and abilities of people with developmental disabilities. The training included an exploration of people's feelings about working with this population, an explanation of developmental disabilities, with an emphasis on how to help someone with a disability. The training also stressed promoting independence rather than "doing for them." The participants spoke about their disability, their needs and abilities. Two issues which arose included helping a person at lunch and in the bathroom and "how much help to give." The trainees were taught how to set limits and say "no" in a dignified and respectful manner.

The formal training occurred once per month for the three months. Follow-up sessions were held as issues and questions/concerns arose. One training session included, a visit to the workshop and the participants' residence was held.

The recruitment process included the following:

Articles in local newspapers (however we

did not get any community referrals from these articles).

- Applications filled out by developmental disability agencies.
- Program directors interviews of participants to determine an appropriateness match with the participants and the senior center.
- Site visits with agency staff and participants to show the participants what occurs in a senior center.

We found that the barriers to recruitment fell into one of two types: institutional and eligibility. Institutional barriers were present when: (1) agencies were reluctant to allow their participants to retire because of funding constraints (fear of losing funds if the required six hours of "active treatment" as defined by government agencies were not provided), (2) when regulatory issues such as state and Medicaid regulations did not easily allow for retirement, and (3) when only limited transportation services and funds were present.

Eligibility barriers were present when: (1) the seniors being referred were not travel trained, had toileting problems, or their functional skills were markedly below the norm of the other seniors; (2) some of the seniors who were referred demonstrated inappropriate social skills and behaviors; (3) some of the seniors who were asked to participate did not want to retire; (4) there was resistance to change in program by potential participants or a family member; (5) the senior's disability was sufficiently severe so as to impede participation; or (6) the senior being referred was physically ill.

The program director met with each potential participant to assess his/her interests and abilities and to review his/her choice of centers/activities. People were matched with senior centers based on their interests and needs and the scheduling of the senior centers. The director attended the senior center with each participant on his/her first day to help him/her get acclimated.

By the end of the first year, eleven people with either mild mental retardation or cerebral palsy were attending four JASA senior centers. They participated in arts and crafts, dancing, a choral group, a music appreciation class, yoga/exercise, bingo and lunch.

Some of the participants were more dependent in the beginning than anticipated and needed extra help from staff and volunteers. A few had questionable social skills and exhibited inappropriate behaviors (e.g., taking the microphone during a music class, demanding too much of volunteers, standing right next to the speakers during a class, and asking the volunteers to act as messengers between the participants and the program director). These problems were addressed with the help of the developmental disabilities' agency staff.

The relationships between the participants and the center members developed slowly. At first, the participants relied on each other for support as they became acclimated to center life. Then, the participants began to make new friends as center members became less fearful of them. Some center members did not want the participants to sit with them at lunch, but over time they "accepted" them as members of the center. In one center, where there were many frail and disabled elderly adults, the participants with a developmental disability made friends easily.

Productive relationships between volunteers and participants evolved over several months. While volunteers initially were overly solicitous and paternalistic, they learned to set appropriate limits respectfully and with dignity. As a result, the participants became more independent.

Lessons Learned

A supportive and cooperative senior center staff is the key to the success of any community integration effort.

Due to the large staff/center member ratio (two to 85 to 200 members), volunteers were needed to assist participants in each site. Two center



directors had previous experience working with people with disabilities. The other two received training. The role of the center director was to welcome and register the participants as new members and generally to supervise their visit to the center.

Direct contact with agencies resulted in referrals, however, press releases were ineffective.

We found that many of the developmental disabilities agencies were reluctant to refer participants out of their programs for fear of losing government funding; reimbursement is generally based on some set number of hours of "active treatment" and within some agencies leisure activities are not yet considered active treatment.

Mainstreaming one person at a time can be more effective than mainstreaming a group.

Too many people at one time (depending upon the extent of their disabilities) can be overwhelming to the staff, volunteers, and center members. A developmental disability agency staff person's presence can help to acclimate the participants to the program and can help to resolve any problems/conflicts which arise. However, at times the participants would cling to the staff person when present and would not become involved in activities.

Agencies which serve older adults can serve the needs of people with developmental disabilities.

Cooperation between the aging and developmental disabilities networks is essential for an integration project to succeed. Transportation must be provided and case managers from developmental disabilities agencies need to be involved in working with the participants in the mainstreaming effort. The program was successful where JASA staff and the staff of the developmental disabilities agencies worked cooperatively.

Such integration efforts must be planned to meet the needs and abilities of the individual participants. Some older persons with developmental disabilities who are in workshops feel strongly about wanting to continue to work and are reluctant to retire, whereas, others feel ready for alternative (leisure) activities.

Parting Comments

In our case, it was important that the developmental disability agencies work together to assess the participants' needs, interests and abilities. It was also important that the developmental disability agency staff be available to assist the program personnel as the program gets under-way. The participant's case manager and either the occupational or art therapist made several visits to the various sites in the beginning to provide support. It is helpful to the centers if they are made aware of any problems which the participants may have and what that person's program goals may be.

Older people with developmental disabilities can benefit from participating in community-based senior programs. Volunteers are needed to help make an integration effort work, particularly if a large number of people are being mainstreamed. Cooperation between the staffs of aging and developmental disability agencies is essential to ensure the success of the program.

It is beneficial for all older adults to have as many choices as possible as to how to spend their later years. Older adults with developmental disabilities are no different. Opportunities need to be created which allow such individuals to spend their leisure years productively. There is a role to play for senior agencies in providing opportunities for recreation and leisure. We believe that there should be a partnership established between the aging and developmental disabilities networks.

JASA's program has enabled its eleven participants with developmental disabilities to begin developing new relationships with people their own age. It is a beginning towards helping them to develop and discover new skills or rekindle old ones; and it is a step in the direction of helping them to become more independent and diminishing their dependence on an agency.

Center Ventures

The most common community resource available to older adults under the Older Americans Act is the community senior center. Senior centers are sites often located in neighborhood buildings, such as surplused schools, churches, apartments, neighborhood social centers and even store fronts, that provide a social environment for seniors that encourages congregation and participation in various activities. Many senior centers are also congregate meal sites, or multipurpose buildings which offer avocational activities, work or craftshops, and physical exercise/fitness facilities. Many have already undertaken efforts to reach out to seniors with disabilities; others have yet to do so.

The case studies that follow are examples of efforts undertaken to aid older persons with developmental disabilities to use the services at their local senior centers. As would be expected, this is the most prevalent community integration effort generally undertaken and as such offers the broadest variety of experiences. We have included a variety of examples of such experiences in this section.

Readers will note a diversity of approaches. Some worked to aid the senior center to become a more receptive environment. Others took steps to aid one or more seniors with a developmental disability become more familiar and more at ease with using their neighborhood's senior centers. Still others found that the only way they could get their "foot in the door" was to set up an enclave program. Some also undertook their efforts with project staff, others did staff sharing arrangements, and still others used a senior friend or companion approach. Some formal arrangements were tried, others went ahead on their own. Others used a matchmaker or broker approach that paired seniors with the center most suitable to their interests and needs.

These varied approaches provided us with a richness of experiences from which to draw. We were pleased with the diversity as it showed that there were many approaches that work to the advantage of seniors with a developmental disability, but that there is no one "correct approach" that will work for all agencies.

The lessons learned? Given the number of such efforts, the lessons learned were abundant and varied. Many of the efforts to use senior centers can be done at little or no cost. Such efforts go much further if you do not run into resistance on the part of the site managers or other seniors routinely using the site. Although the force of law is behind your efforts, you do not "score points" by forcing people to accept one another. Volunteers, particularly other seniors, functioning as senior friends, can be a valuable resource. Aiding individuals to be integrated into senior centers can be more effective than attempting group integration. On the other hand, if nothing else will work, then aiding a group to become site users is a workable device. As one of our contributors noted: "If at first you don't succeed, try again!"

WACOSA Seniors Program

Pamela Baltes¹

Case Abstract: This case study describes the experiences of a disability agency in St. Cloud, Minnesota in establishing a program for seniors with developmental disabilities within a community center. The program provides skill training in communication, hygiene, community integration and recreation/leisure. Seniors are involved in activities within the center and in the community such as: exercise classes, study groups, and volunteering in a nursing home. It was found that the program is cost-effective and that training the seniors in the "hidden rules" of the center is helpful in promoting acceptance of them as participants.

Introduction

WACOSA is a private non-profit organization incorporated in 1963. It is licensed by the Minnesota Department of Human Services to provide vocational and habilitation programming for 130 persons with mental retardation and other related conditions.

The name "WACOSA" is an acronym formed from the location names of the primary program sites (WA-Waite Park, CO-Cold Spring, SA-Sauk Centre). A fourteen member board of directors governs the operations. Currently, WACOSA employs 27 training staff and 17 support staff who work with individuals assisting them to become more independent and self-sufficient. Although WACOSA has a strong vocational emphasis in its program, a newly formed seniors component has allowed elderly individuals the opportunity to integrate socially with other seniors in the St. Cloud area.

St. Cloud is located in the central part of Minnesota. A small community situated on the Mississippi River, the population of St. Cloud is about 48,000.

Project Description

The WACOSA Seniors Program consists of 14 seniors who have developmental disabilities, two full-time staff, volunteers and student interns. The age range for these 14 seniors is 53 to 86. There are five males and nine females. Living arrangements include board and care homes, foster homes, nursing homes, ICF/MR

group homes, and parental homes. All but one of the seniors are ambulatory. Transportation is provided by specialized services, taxi and WACOSA vans.

The frequency of attendance is determined at annual staff meetings. Seniors can attend one to five days per week. Currently, all our seniors attend on a regular schedule except for occasional days off for vacations or illness.

The Seniors' Program is located in the Whitney Senior Center in St. Cloud, Minnesota. The program includes training in such skills as communication, hygiene and self-care, community integration, and recreation/leisure.

Seniors are involved in as many integrated activities at the Whitney Center and in the community as possible. Some of these activities include exercise classes, daily meals in the nutrition program, bi-weekly involvement in the wood shop making toys for tots, a humanities study group, and volunteering at the humane society where they clean pet cages and play with the pets; a nursing home where they provide assistance with passing out juice and playing bingo with the residents; and using the public library, community stores and attending special events.

In the Fall of 1989, WACOSA administrators met with the director and staff from the Whitney Senior Center to discuss the possibility of creating a program that would allow seniors with developmental disabilities to be integrated within the general senior population. The Whitney staff were somewhat familiar with



Correspondence should be addressed to Pamela Baltes, Program Manager, WACOSA, 620 Sundial Drive, Waite Park, MN 56387.

WACOSA as many of our seniors had been accessing the nutrition program for several years. The staff from the Whitney Center was willing to help and eager to have the group move into their building.

The first step was to enlist the help of a consultant with knowledge and experience in seniors' issues. Dr. Ellie Stokes, a professor of Anthropology at St. Cloud State University, agreed to assist us. Dr. Stokes first conducted observations at WACOSA to assess the skill, strengths and deficits of the seniors. She also made comparison observations of seniors frequently using the senior center. She then made recommendations to help alleviate some of the potential barriers to a smooth transition of WACOSA's senior group into the Whitney Center. Her recommendations included

- adjusting our dress code to fit the Whitney Center;
- learning the use of appropriate table manners:
- · using appropriate greetings; and
- locking the door when using the bathmom

Dr. Stokes also suggested that we discuss the proposed integration with the most active members of Whitney. Through these conversations, active members were able to share their concerns and ideas while WACOSA gained member support.

An example of the impact this program has had on some of the seniors can be clearly seen in the vignette of Ms. Mary Jean F.

The WACOSA seniors moved into the senior center in November 1989 after three months of planning. The individuals who moved into Whitney continue to be categorized under the existing Developmental Achievement Center (or "DAC") license and are technically still at WACOSA and just visiting the senior center daily. The funding remains the same for each individual based on where he/she lives. Com

Ms. Mary Jean F.

When 61 year old Ms. Mary Jean F. reentered the WACOSA program she went directly into the Whitney Senior Program. Upon entering the program, her history of incontinence, non-compliance, uncontrollable crying, minor outbursts of physical and verbal aggression, and no expressed interest in interacting with her peers or with her environment was a problem.

Now, after one year in the seniors' program, Ms. F. has become a "model senior". She is an active member of the Retired Seniors Volunteer Program, sets tables at the nutrition center daily, is learning to ride the Metro bus, plans group activities for herself and one or more of her peers, volunteers to deliver meals to those unable to cook for themselves and is looking into joining a seniors' chorale group.

We feel that Ms. F.'s phenomenal changes in both her behavior and attitude are due, in part, to a more stable environment and proper medical care. We also believe that her success is strongly tied to our senior staff using "forced choice" options to involve her in the program. When she completed the required number of both group and integrated activities, she would receive one-on-one shopping trips or eating out.

Ms. F.'s crying behavior was ignored and she received immediate and frequent reinforcement for appropriate interactions and expression of her feelings. She became responsive to the various friends and acquaintances who would occasionally stop by to visit the seniors.

While Ms. F. still requires some motivation to do independent activities, we see no more crying, nor the mood swings or depressions. She has become a social person.



mon funding sources include county and state money through the Minneasota Community Social Service Act, home and community waiver services, Medical Assistance and private pay.

WACOSA does not have to pay rent or is responsible for any other expenses at Whitney Center. The only additional expense that we have undertaken is a private telephone line to prevent "overloading" the Whitney Center's telephone system.

The group is comprised primarily of individuals who are over the age of 60. Two of our regular staff are running the project and receive assistance from volunteers, student interns, and Green Thumb workers. (Green Thumb is an employment organization for seniors that places people in jobs.) These staff are supervised by a program manager from WACOSA.

Lessons Learned

A move to a senior center can be cost-effective

We do not pay extra for the space. Our only additional cost is for the telephone. Moving 14 people out of the current building allowed WACOSA to increase its capacity and accept referrals for 14 others.

Access built-in communication tools, such as newsletters, to let people know what you are doing and express appreciation for support.

This way you will be able to meet with the center staff consistently to "field" problems and stay current with the center's issues and assist the center with its needs.

Train your seniors in the "hidden rules" of the center.

Rules, as do not talk in the halls when a card club is playing, lock the bathroom door when using the bathroom, and do not walk into offices or rooms where other groups are meeting, are helpful advice to give to your seniors. Do not expect center employees to take responsibility for the seniors.

Be aware of where your seniors are and that senior center staff do not generally provide personal care or special assistance. Help the seniors get involved with other activities.

For example, help them join the Retired Senior Volunteer Program, eat meals at the nutrition program site (even if it is a bag lunch), and go outside the center for integration activities by attending group activities and lectures only when you can provide adequate supervision. Join forces with others in the field who are doing similar activities by meeting with the activity directors of nursing homes or adult day care center to share ideas, activities and resources. Most importantly, in all integration activities, be sensitive to the individuals you are with and try to make the experience positive for both perons who are disabled and those who are not.

Parting Comments

Program administrators who are interested in developing similar programs within an existing senior center can help to facilitate successful integration by assuring two things:

- The seniors who attend the centers should "buy into your project."
- Do not try to force others to accept the group.
 Ask their advice, let them know exactly how many people will be attending and what kind of activities you are planning. Build in an open communication system before you start and take every complaint and suggestion seriously.

The move to the senior center has been successful for our seniors and an educational opportunity for many community members. Some of the myths and fears about people with handicaps are disappearing as the public becomes used to us being in their environment. We continue to strive toward more independence within the center and more normalized activities. It has been a learning experience for both the public and our staff.

Liberty Center Project

Patricia A. Wade¹

Case Abstract: This case study describes the experiences of integrating seniors within several agencies and cultural activities in Hamilton, Ohio. A satellite program was housed in an urban area senior center by a disability agency. The disability agency integrated people from a segregated program into the onsite senior center. The project found that solving staff and supervision problems by providing the necessary staff and qualified supervision as keys to their success.

Introduction

During the 1980s, full community integration emerged as a goal for the programs operated by the Butler County Board of Mental Retardation and Developmental Disabilities. The Board's philosophy and efforts have progressed from taking individuals with mental handicaps to community activities in groups merely for them to observe, to these individuals actually accessing generic services. Now, many of these individuals with mental handicaps are employed or volunteer at several community locations and often live in the community with their peers who do not have handicaps. What we now realize is that integration, or the mere physical presence of individuals with mental handicaps in the community, is not enough: we now strive for "inclusion," or presence in the community that results in personal relationships and friend-

When seeking an appropriate community setting in which to facilitate the inclusion of an older individual with mental retardation, we looked for commonalities between individuals who do not have handicaps who frequent a particular setting and individuals who have handicaps who are targeted for inclusion. For older individuals with mental handicaps, one environment for this inclusion which has existed for over twenty years is the senior center. The traditional function of senior centers has been to develop personal relationships and friendships among older individuals. Thus, these offer an atmosphere in which to promote inclusion for seniors with mental handicaps.

The Liberty Center Project sought to establish a satellite program for older adults with

mental handicaps at a local senior citizens center. The seniors previously received services in segregated county programs for individuals with mental retardation. The project was initiated to integrate older individuals with severe mental retardation not only into a physical setting with senior citizens who do not have mental retardation, but as full members with the same expectations as any member: contribution, respect, and participation.

This case study takes place in Ohio's Butler County, an area of some 291,000 persons in the greater Cincinnati region. The communities of Middletown and Hamilton-Fairfield represent areas of some 70,000 and 140,000 persons, respectively.

Project Description

The Liberty Center Adult Services program staff recognized the potential of senior centers to provide appropriate services for seniors with mental retardation during the early 1980s. Contacts were made with those individuals who provided services and conducted programs for older individuals, as well as with university officials who specialized in gerontology studies. These early efforts focused mainly on information gathering rather than on integration. A geriatric assessment tool was developed for older individuals who were enrolled in Adult Services. The population that was targeted was based on the individuals' age for specialized senior services. These individuals were enrolled in two workshops within the county -- the Middletown Center and the Hamilton Center. We thus made special efforts to reach out to community senior centers.



Correspondence should be addressed to Patricia A. Wade, M.Ed., Program Supervisor, Liberty Center Adult Services, Butler County Board of Mental Retardation and Developmental Disabilities, 5645 Liberty-Fairfield Road, Hamilton, OH 45011.

In 1986, a group of Middletown Center older adults began making weekly visits to the Middletown Senior Citizen Center to have lunch and participate in center activities (see Middletown Community Integration Project). Then, in early 1987, the Program Coordinator of the Hamilton - Fairfield Senior Citizens, Inc., and I met to discuss the possibility of bringing seniors who had mental handicaps to the Hamilton - Fairfield Senior Citizens Center for activities. The program coordinator's response at that meeting was very favorable, however, she noted a few limitations. First, we were asked to provide staff or escorts to assist our service recipients with personal needs and, second, we could not automatically expect a warm reception from the center's other users. The program coordinator was very emphatic in stating that this is not a population known for its flexibility.

Early in 1987, two Hamilton Center service recipients made two trips to the Hamilton -Fairfield Senior Center. However, this activity was discontinued due to a lack of available staff and transportation. The individuals from the Middletown Center, however, continued to have success in accessing the Middletown Senior Center. Two favorable conditions that helped facilitate the visits were that they were more highly skilled and had less severe disabilities than many of the other service recipients, and the existence of convenient door-to-door public transportation. In addition, formal in-house work groups on aging that were established in 1987 at both facilities using a curriculum that focused on the needs of this population helped make our staff more aware of senior issues and needs.

In 1989, the Liberty Center opened a program for adults with profound and multiple disabilities. Because many of the adults were older, it was decided to establish a seniors group for older Liberty Center participants which focused on the needs of these individuals. In December 1989, the instructor who was responsible for the Liberty Center's senior group again explored the feasibility of having the seniors visit the Hamilton-Fairfield Senior Citizens Center. By January 1990 she began taking two or three seniors for regular weekly visits. When

visiting the center, the Liberty Center seniors participated in a number of activities, including crafts, ballroom walking, lunch, and movies. Occasionally, when nothing specific was scheduled, they merely socialized in the living room. Soon the Liberty Center's seniors and staff became a familiar group at the Hamilton-Fairfield Senior Center and were graciously accepted by the staff. Acceptance by the constituents, as the program coordinator predicted, was slow in forthcoming, but an occasional overture of friendship was made.

A firm commitment was made in 1990 to make every effort to continue the participation at the Hamilton Senior Center, and in June 1990, a decision was made to explore the possibility of establishing a satellite program for seniors with mental handicaps to be housed at the Hamilton-Fairfield Senior Citizens Center. In July, the instructor and I met with the program coordinator in order to introduce the suggestion as well as to explain the philosophy motivating the idea and to seek ways materials, staff and services could be furnished in order to make this step a reality. To our gratification, the idea was very well received, and a subsequent appointment was made to meet with the executive director who was also very much in favor of the concept. She explained that integrating seniors with handicaps into their program would, along with the salutary benefits of inclusion for individuals who have and do not have handicaps alike, provide additional benefits to the Hamilton-Fairfield Senior Citizen Center and to the Council on Aging which is housed at the Center.

By December 1990, the executive director of Hamilton-Fairfield Senior Citizens, Inc. (S.C.I.) retired. Her replacement agreed to proceed with the project to integrate seniors with mental handicaps at the senior center, and set up a meeting with the Butler County Board and the S.C.I. attorneys and executive staff. From that very positive meeting, the following points of agreement emerged:

 The Board would provide financial resources to the center (approximately \$25,000) for the completion of one of the rooms on the center's second floor. This room could serve as a "home room" for up to twelve seniors with mental retardation and enable informal and regular integration into the other activities of the Hamilton-Fairfield Senior Citizens Center. These activities were agreed upon by both parties

- Integration into the activities would be the sole responsibility of the staff of the Board who would supervise, assist, and be responsible for their seniors.
- The Board agreed to provide a one-to-four staff/senior ratio for supervision at the center.
 The seniors with mental retardation were to apply for individual membership, thus, becoming full members, with all the rights and responsibilities thereof.
- Transportation to and from the center for the Board's seniors would be provided by the Board.

Funding for the renovation project was provided by the Board, which had encumbered the monies in the Liberty Center Adult Services budget. In return for the funding, Hamilton-Fairfield Senior Citizens, Inc. agreed to allow the Board exclusive use of the room for five years. A Memorandum of Understanding covering the terms of the agreement between the Board and Hamilton-Fairfield Senior Citizens, Inc. was signed by both parties in June 1991.

The collaboration between the Butler County Board of Mental Retardation and Developmental Disabilities and the Hamilton-Fairfield Senior Citizens, Inc. was a unique arrangement. As neither the Board nor S.C.I. had a precedent for such an arrangement, conscientious attention was given to the development of the project by the executive director of Hamilton-Fairfield Senior Citizens, Inc., and the program supervisor of Liberty Center, who were to be the project liaisons.

Policies were adopted that anticipated and addressed possible barriers to service provisions, including procedures for appropriate integration into center activities, adequate supervision of the service recipients while participating in a center activity with peers who did not have handicaps, and responsibility for ongoing maintenance of the room and materials used by the seniors with mental handicaps.

The most challenging issue was who would supervise the Board personnel who now worked at the senior citizens center. Because these staff were subject to regulations of the Board, Hamilton-Fairfield Senior Citizens, Inc., and a collective bargaining agreement, a personnel handbook was developed to address the needs of this group in order to minimize problems and conflicts in personnel policies. We made sure that a policy of one entity was not contrary to or a violation of a policy of another entity. Given this, should a conflict arise, a satisfactory compromise could be worked out.

To begin the project, we worked with eight Liberty Center seniors with mental retardation to draw them into the new program at the senior citizens center. Direct care was provided by two habilitation assistants, with supervision by a certified instructor. The assistants worked full-time at the senior citizens center, the instructor worked half-time at the senior citizens center, and half-time at a Board facility, leaving the assistants to proxy supervision while the instructor was absent.

The activities in which the seniors engaged while they were at the senior center were mutually agreed upon by the Board and the senior center. These activities included care-giving, daily living and social skill training, and other typical "senior" activities. The latter -- which whenever possible were integrated with nonhandicapped seniors -- more than likely included such activities as arts and crafts, physical fitness, dances and socials, games, lectures and educational activities, lunches, and field trips. Although our seniors were assisted in these activities by Board staff, the long-term goal was to promote friendships with the regular members of the center with the idea that they would eventually supplant the staff to assist their friends.

As this program was a typical "senior" program, it did not include opportunities for paid production or vocational training, therefore only



those seniors who were no longer interested in these activities were considered for the program.

The Liberty Center continues to provide a transition program for its seniors with mental disabilities at our facility and in the community, while we work to fully establish the satellite program at the senior center.

At the Liberty Center program site, our seniors engage in activities such as arts and crafts; assist with cooking and baking for special events; coffee hour with discussion of current events; relaxation exercises such as water and lotion massage and listening to tapes; physical development activities such as warm-up exercises, walking, and dancing; various leisure activities and games; as well as instruction in self-help and vocational skills, if they so desire.

The seniors also visit the Hamilton - Fair-field Senior Citizens Center twice a week where they participate in such activities as ballroom walking, blood pressure check, library-mobile, exercise class, and lunch with the other members.

Because the seniors at the Liberty Center have profound and multiple disabilities, when they access the community it is with a one-onone escort. They may also go to a cinema, a restaurant, the public library, a store, a shop, or the mall to make a purchase, or to attend a public event. They have taken classes at a local craft shop and participated in volunteer work for the county litter control program. They have also been participants with other seniors who do not have handicaps in events slated especially for seniors such as regional "senior expos" at local amusement parks, a senior art show at the Cincinnati Commerce Center, the "senior olympics" at a local retirement center, a senior walka-thon to raise money for vans, bus tours to local places of interest, riverboat rides, and the Cincinnati Ballet Sampler Series. Through the Cincinnati Arts and Humanities Resource Center for the Elderly, our seniors have been able to attend jazz and musical theater presentations with their peers who do not have handicaps.

Various modes of transportation have been used to access community resources, among them being Board program buses, the Liberty Center bus -- which staff drive -- and private cars. Public transportation in most of Butler County is limited and therefore is used infrequently.

The instructor who works with the seniors, has received information and support from various agencies which deal with the elderly. She holds membership in The Arts and Humanities Resource Center for the Elderly, the Council on Aging, the Ohio Department of Mental Retardation and Developmental Disabilities, Southwest Regional Sub-Committee (for geriatrics), and the Cincinnati Activity Coordinator Council. She has also received much assistance from the Council on Epilepsy, Easter Seals, the Mental Health Association, Maple Knoll (a retirement center), the University of Cincinnati, and the United Appeal (Community Chest).

Lessons Learned

Aging network receptivity is important to making integration efforts work.

Although some senior center members may have their own prejudices and feelings about other seniors, irrespective of the nature of their differences, winning the cooperation of the center administrators and staff is crucial. It is also important to show good faith by staff sharing, budgetary assistance and other cost sharing efforts -- senior center programs generally do not have a large endowment and can benefit from any infusion of funds or other resources.

☐ A formal structure between the senior organization and mental retardation/developmental disabilities service providers may be needed.

Although we worked out a formal arrangement, it is not always necessary to do so -- many informal arrangements can work just as well. In our case, because we were engaged in staff sharing and a specific budget transfer, we needed to cover employment contracts and other areas of potential conflict.

Parting Comments

Our program is in transition, yet much has already been accomplished. Soon, in addition to a facility-based program which fosters community access for seniors with profound and multiple disabilities, we will experience true inclusion with peers who do not have disabilities for many of our seniors.

In retrospect, the guiding principles which have been most instrumental to success have been the following:

- Develop an inclusion philosophy and communicate it with enthusiasm to all staff.
- · Be assertive when proposing innovative ideas

(the worst anyone can say is "no").

- · Use flexibility in staffing and resources.
- If it takes one staff trainer or escort to make a program successful for one senior, be prepared to provide it.
- Use any transportation available to access the community, including walking; appeal to "image" and benefits to the organization when proposing integration with a community entity.
- Cite previous successes and build on them.

SARAH, Inc.'s Elder Enrichment Program

Laurie-Jean Dittmann¹

Case Abstract: This case study describes the experiences of an agency in rural Connecticut which has successfully integrated seniors with developmental disabilities into generic senior agencies in neighboring communities. The cornerstone of this program is the employment of a full-time program manager who worked with many community sites and encouraged seniors with mental retardation to become active members of various senior centers. It was advised to start slowly with senior center administrators, offering the option of only one or two service recipients joining at first. In time, others will become involved.

Introduction

SARAH, Inc. (Shoreline Association for Retarded and Handicapped Citizens) was established over thirty years ago to provide services to individuals with developmental disabilities who live in six towns throughout Connecticut's Long Island Sound shoreline. SARAH's programs offer services to children and adults with mental retardation. The individuals who participate in programming range in age from 2 to mid-70s.

Presently, the agency has a program site located in the town of Guilford (a small community of some 3,600). It is here that people are dropped off and picked up each morning and afternoon. At these various locations and senior centers, they participate in volunteer services, arts and crafts, luncheons, educational opportunities, and religious functions. The focus of the program is to have the seniors from SARAH do as many things as possible as any other senior citizen living in the community. The individuals in SARAH's Elder Enrichment



Correspondence should be addressed to Laurie-Jean Dittmann, Director of Community and Support Services, SARAH, Inc., 33-R Water Street, Guilford, CT 06437.

Program (EEP) range in age from 56 to 77 with the average age being 65. There are currently seven females and three males. The participants live in private homes, group homes, and nursing homes.

In the spring of 1989, SARAH'S vocational program was about to undergo a dramatic change. For many years, SARAH had been providing vocational programs through small businesses. As the agency was contemplating closing its greenhouse (where many of its seniors with mental retardation were employed) the seniors were asked about their vocational aspirations. The majority of the seniors expressed the desire to retire or semi-retire. We were embarrassed to admit that we had never offered retirement programming as an option. Thus, SARAH's Elder Enrichment Program was designed.

Project Description

The EEP is a day program which is held Monday through Friday. The program participants are transported to the program by group home staff or by SARAH's transportation program. The EEP program strives to provide a community enrichment experience for individuals who are fifty-five years of age and older. At the present time, there are 10 participants in the program. The amount of time spent participating in the program is dependent upon the needs and desires of the participants.

Once it was determined that we were going to open the EEP program for seniors, one of the full-time vocational program staff people was offered the opportunity to manage it. At that time, we also decided to incorporate the EEP into the Community and Support Services division of SARAH. This fit has been perfect as one of the purposes of the program has been to focus on community enrichment and not to have anything to do with vocational planning.

The full-time manager began her responsibilities in August 1989. As SARAH's focus has always been on community presence, the program manager visited many senior centers

and other community sites in search of support. As Guilford has always welcomed SARAH and since the base of operations for EEP was located there, we had very positive responses to this new venture.

When the EEP manager approached the Guilford Senior Center, the idea of having our program as a part of its program was accepted with enthusiasm and encouragement. Currently, every service recipient involved in SARAH's EEP program has become a member of the Guilford Senior Center.

Each individual served by SARAH is in the vocational, residential or day services such as EEP. Each of these individuals has a set of goals and objectives established on a yearly basis which are reviewed quarterly. Through the review process the individual's program services can change. The annual review process is a critical tool for determining appropriate service placements for individuals. Special reviews were held to coordinate the necessary changes to get the first few service recipients started in the program.

In October 1989, the first older adults with developmental disabilities attended the program. Most attended on a part-time basis as we were only able to afford one staff person. As more participants have desired to take part in the program, a part-time staff member was hired in August 1990. Presently, with one full-time (40 hours a week) and one part-time (20 hours a week) staff member, the program has expanded to serve ten individuals. Many are full-time while others attend part-time. It has often been decided that part-time attendance in EEP is in the service recipients' best interest. We do feel. however, that if we could secure funding for more staff, all participants would benefit by attending this program full-time.

Having two staff people allows for the program to be split into small groups. In this manner, there are never more than four seniors from SARAH's EEP program at a community center at one time. When not participating at one of the centers, the other members of EEP participate in activities such as going shopping, dining



out, visiting museums and galleries, going on boat rides, partaking in pet therapy, picnics, religious affiliations, crafts and volunteer services. Our seniors are never idle, nor do they seem to be bored.

Because the program began after the fiscal year started, there was no cost center or line items in the agency's budget specifically for EEP. SARAH's finance department needed to rewrite the budget to reflect the program's expenses and income in the Community and Support Services Division. Funding for EEP comes from a contract that SARAH established with the Connecticut Department of Mental Retardation. Funds are set on a per consumer per diem rate.

Lessons Learned

You have to work at gaining acceptance and promoting inclusion

By continuing to maintain a positive attitude and being persistent, our manager will eventually encourage our seniors with mental retardation to become active members of all our senior centers. Visiting a center with one or two seniors at a time and inviting administrators to various programs or at other senior centers where SARAH members are involved, will help to alleviate any skepticism the administrators may have.

Parting Comments

Our successes with EEP have been numerous. We have truly been accepted into the shoreline community. The town of Guilford has looked to us to be active members in its senior program. Through this program we have had the opportunity to participate in such activities as concerts, movies, crafts, line dancing, bingo, sing-a-longs, lectures and various other committees. Our seniors have had the opportunity to be volunteers and in a sense have given back to the community. They volunteer for such activities as Meals-On-Wheels, the American Red Cross, the Red Ribbon campaign for MADD, and a food bank.

We have participated in senior centers in five other shoreline towns as well. There is one center in our six towns that does not seem receptive to the idea of having individuals with developmental disabilities participate in its programming. Our manager is persistent and will continue to visit this center in hopes of changing the administrators' minds.

Our biggest problem at this time is lack of funding specifically ear-marked for EEP. So many seniors want to take part in our program that there is a waiting list. If we could afford two full-time employees and/or another part time position, we could serve more people. We try to utilize volunteers and students as much as possible. We hope to put the program on separate funding base eventually from DMR and to bill it as an OOA (Opportunities for Older Adults) program.

In addition to staff salaries, other costs include: rent, utilities, administration, transportation and supplies. The service recipients pay their own dues to the senior centers which is usually a very nominal fee. They also pay for the activities in which they participate. Their share of costs for activities includes a portion of the admission or entrance fees for staff and volunteers. Service recipients also bring their lunch unless there is a planned activity at a restaurant. Volunteers, family members, civic organizations and school groups can all be valuable assets as possible funding sources.

Our recommendations for programs starting up would be to "really do your homework!" Establish eligibility requirements such as age, place of residence, time available for a seniors program, accessibility needs and medication requirements. Visit as many local senior centers as possible. Be as positive as you can -- offer to these centers what individuals with special needs can do as members. If you need a base site, locate it in an "active" town -- within walking distance of local shops, libraries, and other businesses.

Start slowly with senior center administrators. Offer to have only one or two service recipients join at first. As time goes on, other



seniors with special needs can become members. Always keep your groups small. A staff/participant ratio of four-to-one is the maximum. Meanwhile, invite seniors and administrators from various community centers to agency functions such as parties, open houses and fund raisers. Likewise, ask your service recipients what they would like to do. Offer them many choices. Too often individuals with mental retardation have their decisions made for them regardless of their age. It is extremely impor-

tant that professionals remember to talk to the service recipients and to explain to them their many options.

All programs should strive to be fully integrated. SARAH's EEP has done just that. Having a positive attitude and community image has also helped with the transition into community programs. All senior citizens, regardless of their special needs, deserve to participate in age appropriate, life enriching experiences.

Senior Special Needs Activities Program

Sandra Vadnais¹

Case Abstract: This case study monograph profiles the three year effort of a group of disability agencies in using a senior center in a rural community in Wisconsin. The project used United Way funds to get pilot integration efforts underway enabling a small group of seniors use the facilities of a community senior center. The project found that proceeding slowly with a pilot group provides a good degree of success and that cooperative ventures linking a disability agency with a senior center can work.

Introduction

By the mid-1980s, Dunn County, Wisconsin service agencies were already discussing the need to include people with developmental disabilities who were of retirement age into senior citizen programming available within the county.

A consortium of supporting agencies was formed in early 1988, which included Dunn County Human Services, the Office on Aging, Menomonie Senior Center, Indianhead Enterprises (a sheltered workshop facility) and the University of Wisconsin-Stout Center for Independent Living. A recently retired person, with experience in human services program design and implementation, was available to assist with the development of a pilot project to determine the feasibility of providing long-range services

to this target group (approximately 60 identified potential participants).

The Dunn County area is typical of many Wisconsin communities. The area consists of mostly rural out-areas with one or more small towns. The county population is some 35,000 and the population of the town of Menomonie is about 13,500. However, we were also somewhat atypical as we had a university located within the county which has a program known for its interest in rehabilitation services.

To aid us with our effort, we requested funding from the local United Way to cover expenses incurred during this three month experimental project and a University of Wisconsin-Stout Vocational Rehabilitation student to assist the volunteer program developer. Six older persons with developmental disabilities were identified as appropriate participants to try out a



Correspondence should be addressed to Sandra Vadnais, Project Director, SSNAP, Menomonie Senior Center, 1412 Sixth Street, Menomonie, WI 54751.

variety of activities available at the Menomonie Senior Center and to provide ideas for the development of new activities appropriate for the social skill level of this target group. At the conclusion of this summer pilot project, the results were tabulated and presented to the consortium.

The results of the project indicated that there were retirement activities available at the Menomonie site which were interesting and appropriate for people with developmental disabilities who were ready to retire or to reduce their work hours at the sheltered workshop and in supported employment situations. Nutritious meals, pool, shuffle board, craft classes, community touring were the popular choices. As there had been good reception by the center staff, board members and attendees, and several senior citizens had indicated an interest in volunteering for this pilot group, it was determined that Menomonie was ready to support an integration program for seniors with developmental disabilities.

Project Description

A proposal was drafted in September 1988 to serve 16 Dunn County residents age 50 and older, who had developmental disabilities. We used the federal description for developmental disabilities as the criteria for participation and we considered the senior's physical capability to participate. Seniors who had chronic mental illness as their primary or secondary diagnosis were not considered as Dunn County Health Care Center was already providing programming for this population.

The director of the Dunn County Office on Aging was the primary advocate for this new project. She worked with the volunteer project coordinator in writing the proposal and designing a service delivery plan. The final plan was presented and approved by the Dunn County Board of Supervisors for funding in January 1989.

The funding was administered through the County Human Services and contracted out to

the Menomonie Senior Center. The service delivery design emphasized that program participants should be encouraged to choose the retirement activities in which they wanted to participate. This program philosophy was carried through to the referral and intake process so that only people who wanted to participate were referred.

The pilot project coordinator was hired as the funded project coordinator and the project was designated as the Seniors with Special Needs Activities Project (SSNAP). The funding proposal included wages for a project coordinator for twenty hours per week and a contribution to the senior center for administrative assistance.

To ensure that the basic program philosophy of choice (to participate and to choose activities) was supported, meetings were scheduled with Human Services, Indianhead Sheltered Workshop and ARC staff and group home managers. These agencies agreed to refer and support participants who were interested in retirement or reducing work hours, choosing to be involved in the senior center programming. An at-home interview was scheduled with each person referred to the program to explain the program's purpose and to clarify with the individual's group home manager or foster parent the need for coordinated scheduling and ongoing communication. A transportation and activity schedule was developed at this time and a copy of the monthly schedule was posted at the home.

Each new participant was scheduled to begin attending the senior center, to facilitate introductions and to make activity selections in a relaxed and individualistic setting. The project coordinator reserved two-three weeks for each new participant to be "the new person" and to receive undivided attention and evaluation. All senior center staff were sensitized to recognize and support this incubation time as crucial to a positive participation experience.

New participants were encouraged to try a variety of activities and then choose two or more they would like to continue. Problems



identified during this intake procedure were the lack of support and coordination with group home managers/work time schedulers. They appeared unconcerned about the choice factor of our project, and would schedule the participant to come to the senior center on days that were convenient to themselves not to the participant. Rather than have the project turn into a day service, the emphasis was on the choice factor. Communication was increased and coordination improved between agencies so that the seniors could participate on days when their chosen activities were available. The program coordinator arranged to reschedule several activity groups to make them more accessible.

Activities already in progress at the Menomonie Senior Center included ceramics, crafts, bingo, pool and daily nutritious meals. The summer pilot project had developed a weekly community tour and it was decided to add this option to the on-going activities. It continued to be the most popular group activity and has proven to be an excellent method to facilitating integration and encourage decision making.

The project director is licensed to drive a fifteen passenger county van for regular attendees at the senior center as well as residents of a retirement home who are invited to travel along each week. During the tours, suggestions for the following weeks were requested which facilitated the formation of a travelers club. The mixed group elected a president, a secretary and a navigator, which researched community events, historical sites and points of interest.

The group voted on which tours to develop and then the committee planned the trip. Because of the club's success, and the popularity of sight-seting as a retirement activity, this group numbered some twenty to twenty-four travelers per week. Many of the tours included visits to a participant's home town where the participant would be the tour guide and pointed out local sites such as is/her family homestead, church and school. Reminiscing about the "olden days" was a natural outcome of these home town visits and a good way to identify commonalities and facilitate friendships.

SSNAP's Seniors

SSNAP started with six participants attending three activities per week. The initial six participants were a diverse group, including:

- a 63 year old woman who has cerebral palsy, had no formal education, was institutionalized for 25 years and who recently moved into a supervised apartment independent living program;
- a 65 year old man who was legally blind, but who now is experiencing an unusual improvement in his vision, and who attended the State School for the Blind for 18 years and lived in a men's group home for 20 years;
- an 82 year old man who has lived in a foster home for 20 years, who is quite frail but enjoys visiting with people -- especially people he had seen ten years ago at the sheltered workshop;
- an 86 year old man living in a group home who is physically active and walks to the center each day;
- a 75 year old man who lived within his large alcoholic family -- drinking excessively until his parents died -- then lived with a local non-drinking family for 30 years and now resides at a country retirement home; and
- a 65 year old woman, who has only mild mental retardation but a chronic mental illness with cyclical depression, who lived in a group home but was hospitalized after three months. She is now living in a subsidized apartment with a live-in caregiver.

In 1991, funds were awarded to the Menomonie SSNAP program from the Wisconsin Council for Developmental Disabilities "Innovative Project" to develop a "Friendship and Fitness" component. This funding made it possible to add modified exercise classes, walking, shuffleboard and dance classes to the SSNAP agenda. An aerobics teacher developed

a specialized exercising regime and four Senior Companions were trained and subsidized to assist the participants during the fitness activities. Materials from the New York State Senior Companion Manual were used to facilitate the training for these Senior Companions. This sixmonth project is nearing completion, and the Dunn County Human Services has increased funding to SSNAP to continue these physical fitness activities. Three Senior Companions have agreed to continue their assistance on a volunteer basis. The beginning exercise classes were video taped and will be repeated at the six-month stage to document the degree of improvement.

Another popular activity has been the ceramics class. One of the participants, a 63 year old lady who has cerebral palsy, found the ceramics class to be one of the few activities that she could fully enjoy. However, some of the regular center attendees found her voice and her palsied motions too distracting to continue their work. A compromise was achieved by creating a morning beginning class and an advanced afternoon class. There are currently ten SSNAP participants in the morning class which has become fully integrated again, this time by choice.

The Dunn County SSNAP project has been expanded for 1992 to serve 30 people at a minimum of ten hours per person per week. The budgeted plan includes the development of SSNAP services to senior centers in Boyceville and Colfax, Wisconsin. There are currently 26 people actively involved at the Menomonie Center including nine who come to the center for 20 hours per week. Because of this increase, an activities aide has been hired to work 15 hours per week. It appears that SSNAP 1992 will achieve, and most likely exceed, the program goals.

Transportation has been available to program participants who live within the Menomonie city limits by the Disabled and Elderly Transportation System with the Door Stop Bus. However, this service ends each day at 2:30 p.m. and senior center activities continue until 3:00 p.m. or later. We are in the process of overcoming

the transportation limitations by working with the senior center to have one state van designated specifically for the senior center and SSNAP use.

Lessons Learned

Projects that begin slowly have a great chance of success.

SSNAP started with six participants attending three activities per week. This original group was quite diverse (as illustrated in the accompanying box). The diversity of this pilot group, allowed much experimentation with group development and activity choices. It provided a solid platform of experiences on which to base the SSNAP service delivery plan and our workings with the senior center. Had we attempted to begin our project without some initial trials and errors, we most likely would not have had the successes we experienced.

Each senior should be permitted to proceed at his/her own pace.

The Dunn County DHSS needed this activity project to serve its retiring seniors. Therefore, funding was quickly appropriated and SSNAP progressed rapidly. But it remains the philosophy to intake and integrate each person at his/her own pace, and to provide individualized attention until the person is comfortable. The community was also ready for this program, and transportation, although imperfect, was available. We strongly believed that each individual participant had to have a say in what he/she became involved in and to experience some of the successes at various steps.

Parting Comments

This project started on a very small budget because of the volunteer help and the in-kind contributions. However, the budget was not large enough to afford a full-time coordinator. The coordinator position is definitely necessary so that we can continue to provide the current level of services.



The Menomonie Senior Center was an appropriate site to test the first integration project in this area. The center director was a community-oriented person who had developed a solid core of volunteers and center attendees who have continued to support the SSNAP program and its participants. She has been politically involved to assist with increased budgeting and positive visibility within the community. Also, the timing was right for the Department of Human Services to begin reducing the work hours for its aging population with developmental disabilities. Within the last year, they have encouraged twelve people to completely retire and have reduced the work hours for six more people who now attend SSNAP activities. The most difficult problem the SSNAP program has dealt with occurred approximately six months ago when nine residents of the same group home were delivered to the Menomonie Senior Center one day to receive services.

The project coordinator had received a referral on one of these people and had made an

appointment to make a home visit. When she showed up for work one day there were nine new faces, already interacting with other center attendees in the hallways. Needless to say, the whole place was in an uproar and six months later we are still trying to rectify the consequences. It has taken this long to recognize each person as an individual, and to orient everyone properly to SSNAP's purpose. Many of the participants had problems making decisions. Because many of them retired from the sheltered workshop at the same time there were budged problems. Moreover, the group home owner viewed SSNAP as a day service program. However, because there were four Senior Companions available, and other senior center staff and attendees were cooperative, these new participants (ages 55 to 70) are now being assimilated into appropriate activities.

The support and coordination from the organizing agencies facilitated the successful development of this three year old program.

MARC's Opportunities for Older Adults

Kathleen Hull Wickham and Margaret J. Gould¹

Case Abstract: This case study describes the efforts of an agency in Portland, Connecticut which provided a group of seniors with opportunities to participate in a number of activities available in their local senior centers. Solutions to staffing, transportation and crowding problems are identified. The project found special approach to staff training improved participant assimilation.

Introduction

The Opportunities for Older Adults Program was developed as a result of our increased awareness that the participants in our workshop were getting older. They are in their sixties and they wanted to enjoy the activities that retired senior citizens normally enjoy. However, our seniors have developmental disabilities, and re-

quire assistance from others to complete everyday activities. As most of the persons in our target group were interested in other activities besides work, the Opportunities for Older Adults Program was instituted and designed to promote the inclusion of these senior citizens with developmental disabilities into generic community services. What follows is a description of the evolution of interactions between the



Correspondence should be addressed to Kathleen Hull Wickham, M.A., OOA Coordinator or Margaret J. Gould, M.A., President, MARC: Community Resources, Inc., P.O. Box 126, Portland, CT 06480.

OOA Program members and the participants at our local senior center.

Project Description

The goal of MARC's OOA Program is to provide seniors with enjoyable community activities that other senior citizens normally enjoy, such as bingo, lunching out, table games, puzzles, trips, and craft sessions. However, we were concerned about escorting ten people who have developmental disabilities -- of whom one travels in a wheelchair, and five require assistance with walking -- to senior activities with only two staff. Fortunately, we had access to a van which is adapted with a wheelchair lift. However, we had to share the van with another agency program which also served people with mobility impairments. Consequently, the van was only available two days per week.

A community trip to the local senior center to obtain its schedule of activities resulted in the beginning of very positive relationships between our ten seniors and the "regulars" at the local senior center.

Lunch at the senior center was served daily for a nominal fee of \$1.25 per person. Exercise (or "sittercise" as it was called), was conducted on Monday and Thursday mornings immediately before lunch. Our seniors enjoyed the movement, activity, and socialization which occurred during an exercise group. It thus seemed fitting and practical to travel to the senior center for sittercise and then stay for lunch. In order to offer our program members several community outings per week, and with the limited availability of the van, the program instructors decided to take all ten program participants to the senior center two times per week.

In theory, it seemed like a great idea. Everyone in the program would definitely experience two community activities weekly. However, due to wheelchair adaptations, twelve people could not sit comfortably in the van. A group of that size also seemed to be very intrusive to the people at the senior center, who had a set routine and who had never met senior citizens with developmental disabilities before. OOA

staff introduced themselves to the director of the senior center and her assistant director, and together they all discussed goals and expectations of both the OOA program and the senior center. One fact was very clear: MARC's senior citizens had an absolute right to participate in the senior center activities.

The OOA program members and staff attended the Sittercise classes (using the van and a staff member's car) where they met the exercise instructor. He is a very compassionate and easy going man, who is eager to learn with and about OOA program participants. Soon two of the participants began to talk about the "dancing music" during the day. The OOA instructors noticed how the participants seemed to enjoy the sittercise classes. One problem, however, was that our large group used a lot of space in an already crowded room. Also, some of the OOA participants had difficulty keeping up with the instructor's pace. However, all of the staff "plugged right along," though, and gradually, MARC's senior citizens began to feel welcome.

The people in our OOA program looked forward to staying for lunch on the sittercise class days, where they met the kitchen supervisor, and her aide. Both ladies welcomed our seniors, and went out of their way to interact with them and to promote friendships among all the seniors at the center. The food was good, and everyone was asked for their input on the meals.

After several months of attending these senior center functions, our seniors experienced some changes. Mary, who had been ill for some time, became incapacitated and no longer attended our OOA program. Bob, a diminutive quiet man, who was always easy to please, passed away suddenly one weekend. Their loss was felt at the OOA program site and at the senior center. Nevertheless, the OOA seniors continued to attend the sittercise classes and lunches twice per week. Marie, a pleasant, social woman, joined us, followed shortly thereafter by Mike, a quiet man we knew from the agency's work services program, and Carol, a very vocally articulate woman who presented some behavioral challenges.



Thus, the group size grew to thirteen. Because of vehicle availability, it became difficult to escort the entire group to the senior center at one time. Moreover, because too much room was being used by the OOA seniors, it was difficult to integrate them with the other seniors. The OOA staff experienced some turnover and an half-time instructor was added to the team, bringing staff support to 2.5 for 11 program participants.

Every OOA program participant had individualized goals that were worked on regularly. The new instructors reported to the program coordinator that the participants found it difficult to work on participant goals when they entered the community in such large groups. The instructors also had difficulty developing age-appropriate senior citizen activities. Thus, it became necessary to come "down to basics." The OOA staff motto became: "What would my grandmother or grandfather do?" Suddenly, the instructor saw things differently. It was noted that many grandmother or grandfathertype activities were happening already, but there were too many in the group. The only activities staff could name that seniors did in large groups were trips and bingo. Therefore, activities began to occur with smaller groups. Each program member began attending the senior center one time per week with three peers, instead of two times per week with 11 peers.

OOA seniors suddenly seemed to fit more easily into the activities at the senior center, as a smaller group was not nearly as intrusive. One of the members, who was a regular at the senior center, introduced the OOA seniors to several of her friends. Every time any OOA seniors attended the senior center, the other seniors invited the OOA seniors to join them.

In order to maintain or increase the number of community activities and exposure to and from community members, the grandmother/grandfather adage was used. The OOA seniors began going out to lunch at local restaurants in groups of four to five, including staff. Of course, a monthly participant meeting had been conducted to determine what restaurants to attend. The participants frequented the library,

local stores and shops, museums and other attractions. A favorite excursion was to "pick your own" fruit at an area orchard, and then to bake a luscious dessert. Two of the seniors began attending the monthly meetings of the Mid-State Region Department of Aging, and now regularly receive minutes and other important mailings from that department. A new van was acquired for the agency, which was equipped with a wheelchair lift, making it possible for the OOA participants to use a van every day of the program week. Thiss made it possible for OOA program members to experience two to three community activities per week in groups of five or less.

With the increased exposure to the positive atmosphere at the senior center, the OOA instructors expressed the desire to attend some of the other senior center events and activities. Several of the OOA participants liked to play bingo, so four of them attended one of the weekly bingo sessions. They returned to the program raving about how much fun they had, but the OOA instructor who had accompanied the seniors reported that the OOA persons had difficulty keeping up with the quick pace of the bingo caller.

The senior center director approached OOA staff about the possibility of OOA participants assisting another volunteer group in delivering Meals-on-Wheels to homebound elderly persons a few days per week. Consequently, (Tuesdays and Fridays) two of the OOA program participants obtain meals at the center and deliver the meals to the home-bound seniors. The staff from the OOA program and the senior center have found it rewarding to observe those interactions.

Other similarly rewarding interactions have occurred between the two groups of senior citizens. OOA seniors are invited regularly to special functions such as performances by musicians, holiday meals, and other events, which they eagerly attend.

The possibilities seem endless. It appears that some of the OOA members are interested

in attending activities outside the senior center with friends they make from the center.

Lessons Learned

Projects like these can be run at a reasonable cost

The staff-to-participant ratio of 1-to-5 was within practical limits. Revenue to support MARC's Opportunities for Older Adults Program is received from the Connecticut Department of Mental Retardation, and from local community businesses. The annual cost per participant for fiscal year 1991 was \$10,705.00 or approximately \$43.00 per day per person. Transportation costs are expenses which need to be factored into any plan. This OOA Program was fortunate to be able to share other vehicles within the agency. However, in today's economic conditions, this expense could be high if not planned for appropriately.

Hidden costs were few. All program participants were invited and encouraged to participate in all activities of their choice. A person is never denied attendance in an activity simply because of lack of finances. However, participants were asked to assist with "lunch out" costs. Also, since OOA staff participated in senior center lunches and restaurant lunches, they were expected to eat with the seniors. MARC's instructors willingly paid for their meals, but a tightening economy may not always make that possible.

Emphasis should be on participant autonomy and self-sufficiency

In an agency's zeal to foster senior citizen activities, it must be remembered to emphasize participant independence in all tasks as much as possible. Caretaking is not a function of an OOA program, but assistance should be offered on an individual basis as needed. Staff must be willing to think like their grandparents and to try activities that their grandparents would try. Agencies must

promote the notion of the dignity of risk in asking seniors what they would like to do; and then every attempt must be made to access those desired activities. A perusal of specific events or activities should occur before asking seniors with developmental disabilities to attempt those tasks, in order to determine whether the tasks are too difficult or too fast for the program members, and thus avoid disappointing the seniors.

Parting Comments

What began as an experiment within MARC evolved into a permanent program with plans for continued growth. This program required no special guidelines, as it operated within the normal functions of the agency. Its successes and the successes of other OOA and Elder Enrichment programs within Connecticut, coupled with the fact that persons with develop-mental disabilities are living longer, have compelled the Department of Mental Retardation to promote OOA programs as a funding priority.

The organization of MARC's Opportunities for Older Adults Program, and the participation of its members in senior center activities accomplished much more than was expected. Prejudice toward persons with developmental disabilities, and resistance toward their participation in senior activities was much less than expected. A major lesson was learned about the acceptance of community members to the members of the OOA program. People are people, young or old, and that is how our seniors are received and treated.

In addition to adopting a "grandmother or grandfather mind set" when attempting to plan activities for senior citizens, individual participant surveys should be conducted to determine each person's interests and needs. Program coordinators must strongly advocate for the rights of senior citizens, and must be willing to contact state and local departments regarding those rights. Above all, remember to stress individual independence rather than caretaking.



Madison County Integration Program

Christine Sears¹

Case Abstract: This case study describes an effort in a rural upstate New York county designed to aid the integration of a number of older persons with developmental disabilities into community adult day care and senior nutrition programs. The project used influential community individuals to set integration examples at activity sites and other "low key" approaches in facilitating the integration at senior nutrition sites. The project found that integration works well in rural senior programs if "low key" approaches are used.

Introduction

This case study describes a demonstration project funded by the New York State Developmental Disabilities Planning Council (DDPC) which focused on integrating older persons with developmental disabilities into aging day care and senior nutrition programs.

Since 1988, the Madison County Office for the Aging has formally participated in the integration of older persons with mental retardation and developmental disabilities into generic aging programs. Successful integration has taken place in adult day care programs, senior congregate meal programs, a senior recreation swim program and in community day trips for seniors.

Project Description

The integration of older persons with mental retardation and developmental disabilities into generic aging programs (referred to as the integration program), was a demonstration project conducted by the Madison County Office for the Aging. The Office for the Aging in Madison County is a private, not-for-profit agency located in a very rural dairy farming area of upstate New York. The population of Madison County is 69,000.

The goal of the integration program was to successfully integrate eight older persons with mental retardation into the two types of programs mentioned above. Successful integration was defined as involvement and acceptance in an aging program. We also felt that it was important for the person with mental retardation to

be accepted without being singled out by his/her disability.

An integration project coordinator was designated to coordinate the integration effort, conduct monthly monitoring meetings, and provide aging/developmental disabilities awareness activities in the community. Two paid companions were hired to be "special friends" for participants and to assist with integration effort at the site.

The two senior program areas considered for integration were the social model adult day program and the congregate nutrition program. Both programs served the entire county.

The social model adult day program provided a six hour program which consisted of a morning snack, recreation and socialization activities, a nutritious noon meal, and transportation to and from place of residence.

The congregate meal program offered a noon meal for older people. Often seniors would get together before or after the meal to socialize, play cards or work on crafts. Generally, the nutrition program provided about two hours of socialization in addition to a nutritious hot lunch. Both programs are staffed with paid personnel and volunteers from the Retired Senior Volunteer Program (RSVP).

Initially, a monitoring team (made up of local representatives from Sequin Community Services, Madison County Association for Retarded Citizens, Madison County Eldercare Inc., the Senior Nutrition & Country Kitchen Program and the Madison County Office for the



Correspondence should be addressed to Christine Sears, Office for the Aging in Madison County, 43 East Main Street, P.O. Box 250, Morrisville, NY 13408.

Aging) made the participant selections. Guidelines in the selection process for choosing appropriate older persons with developmental disabilities included individuals who were 60 years of age and older, continent, self-medicating, in no danger to themselves or others, and who had appropriate social behavior grooming and hygiene skills.

We felt that it was important, at least initially, for the team to select individuals would be easily accepted at the program sites. Once accepted, we found it opened the door for additional persons to be welcomed into the programs. It is also important to note that while the monitoring team initially determined who was appropriate for a particular senior program, we felt that the final decision was ultimately up to the older individual.

One example of how we built choice into the program is evidenced by a person who chose to attend the social model adult day program and later changed his mind even though he had been truly accepted into the program by all of the other participants. The person decided that he did not want to "be a senior citizen" but instead wanted to go back to work at the workshop. Later, he decided to try the senior nutrition program. He found it to be very enjoyable and now attends at least twice per week.

There was an even ratio of males-to-females in our senior integration demonstration project. The average age of the men was 65 and of the women was 68. Most of the participants reside in community residences or with family care providers.

Once someone is selected to participate in the integration program, it is important to make sure that the initial introduction goes well. Because entering into new situations can be difficult for anyone (whether or not they have a developmental disability), we hired two older persons to serve as companions and discretely assist the participants at the sites. (The participant/companion ratio was one-to-one.) We felt that it was very important not to "red flag" anyone.

The paid companion met with the participant prior to attending the social model adult program. They had lunch together at the site or took time to get to know one another in another location. The intent was to develop a genuine friendship between the paid companion and the participant. When they were comfortable with one another, the participant and companion attended the social model adult day program. The companion did not "stick to" the participant, but was a familiar face and offered guidance or assistance only when needed.

The social model adult day program only operated four days per week. With the success of the integration effort, a one day per week transition program was developed. The purpose was to familiarize the seniors with mental retardation with the social model adult day program. The transition program served a smaller group (eight individuals with mental retardation) and had a higher staff/senior ratio. Becoming familiar with the day care staff, site and routine of the social day program activities created a smooth transition from the sheltered workshop or community residence into the day care program.

Early on we decided not to announce that individuals with mental retardation were going to attend the congregate meal program or the social model adult day program. We felt that the myths and stereotypes risked the success of the integration program. We also found that mental retardation is often linked together with mental illness in the minds of many people.

In the process of integrating people, staff at one site had concerns that people with mental retardation would be attending their program. We did not force the issue feeling. If people who wanted to attend were not genuinely welcome then they would not be accepted. Although we chose not to include that particular site in the program at that time, we did not give up hope.

We tried to use in-service awareness training but this effort did not seem to change the attitudes or the willingness of the site to accept seniors with mental retardation. However, one



day, an influential person in the community served as a volunteer companion to a delightful 63 year old woman with mental retardation. Together they "dropped in" at the site. Although there was some resistance, the companion handled it perfectly. She said "we all have disabilities at our age... I have arthritis in may back and some have disabilities in other places. It just happens that Mary's disability is mental retardation." With that they were able to attend the program.

Site monitoring visits and reports have been very positive regarding Mary's integration into this particular site. Mary offers to help serve lunch to the frail 'typical' participants. She loves to draw and if you attend this site you will see Mary's drawings proudly displayed on the wall. When it is time for her to leave, she waves goodbye to the other participants of the program and hands are seen waving back with cheerful responses like "see you next week, Mary!"

"The nutrition program held its annual picnic at one of our local parks [with over 400 seniors attending]. There were activities, music and, of course, lots to eat. As the musician played, one gentleman started asking various women to dance. Before long there was a long line of women waiting to have their turn. The gentleman was a senior who attends a sheltered workshop parttime and participates in the integration program."

After introduction into either the nutrition or adult day program, the participants with mental retardation have been assimilated very well. As time went on, there was less need for the paid companion to provide assistance. Behavior was rarely a problem. With the excellent communi-

cation between the aging and developmental disabilities networks in Madison County, whenever a problem occurred a remedy was quickly found.

In one case, a man with mental retardation was showing his appreciation to the congregate meal program staff by trying to hug and kiss them. The staff felt very uncomfortable with this situation. We called the case manager from the ARC and sought her advice, she simply stated that all we had to do was calmly say, "John please stop, that's inappropriate behavior." John stopped hugging people when they did not want to be hugged.

Funding for project companions was limited. Initially, two companions were hired to assist with the integration process. We soon discovered that using a "buddy system" worked well. Once participants were comfortable in the senior program setting, they were asked to escort a peer who had never attended before. The participant familiar with the program took pride in showing the new person around and was a friend to them in what was initially a foreign environment. When needed, unpaid volunteers serve as companions to the new participants.

Due to fiscal problems the social model adult day program had to close. The program is sorely missed and has left a void in the community. Many of the seniors with mental retardation who attended the program were introduced to the nutrition program. The transition went smoothly. Others participated in the Senior Swim Program and Senior Day Trip Program. One 63 year old woman with mental retardation went on a senior day trip to the New York State Fair in Syracuse. She had such a wonderful time and was accepted so beautifully, that the senior club which sponsored the trip invited her to go on their next trip which was to Vermont.

Lessons Learned

Communication, networking, and taking risks are all key elements in making an integration program work.



The aging and disability networks must communicate and learn as much as possible about each other. By including other agencies in the project, awareness and additional doors and resources will be opened. In Madison County, RSVP, YMCA and long term care programs have joined together for integration. We continue to learn about each others programs and how they can help our special populations. It is truly a sharing of resources.

In one example, a long-term care facility opened its activity program to community integration. In other, the YMCA developed Super Senior 12 is for the more active older person. Approximately twenty seniors participated, five of whom are developmentally discribes. Activities such as walking, low-impact exercising, painting, presentations on travel and cooking were open to the seniors is participation.

Even the public service announcements identified the Super Senior activity program as being sponsored by the YMCA, Madison County ARC and the Madison County Aging Office, thus demonstrating to the community that we all work together and older persons with developmental disabilities are part of our clientele. Other agencies are observing what is going on and are now offering to participate. It is truly exciting and unique! Taking risks, getting others involved helps to open up new ideas.

☐ Integration programs can be implemented in "low key" manner.

No announcements were made, no giant press releases or blaring trumpets. Instead, it was a very slow, gradual process.

There is no doubt that the integration of older adults with mental retardation into generic aging services is very worthwhile. As an office for the aging, it is our responsibility to advocate for all persons age sixty and over regardless of their ability or disability.

The integration program effort has created an awareness regarding the need for a preretirement program for older persons with mental retardation/developmental disabilities. It also created an awareness of the need to

include older persons with developmental disabilities in the planning of future programs.

Recently, the Madison County Office for the Aging included senior caregivers of persons with mental retardation in its proposal for a Respite Family Grant Program. The Office for the Aging also provides Senior Discount Cards and a quarterly newsletter to all senior citizens.

Parting Comments

As the integration project progressed, acceptance increased. Initially, the goal was to integrate eight individuals with mental retardation/developmental disabilities into generic aging services and after three years we have successfully integrated twenty. Their skills, self-esteem, and behavior improved and friendships were developed with the other seniors who attended the social programs. It is very rewarding to witness what has taken place.

The perfect example happened not too long ago. The nutrition program held its annual picnic at one of our local parks. Over 400 senior citizens attended the program. There were activities, music and, of course, lots to eat. As the musician played, one gentleman started asking various women to dance. Before long there was a long line of women waiting to have their turn. The gentleman was a senior who attends a sheltered workshop part-time and participates in the integration program.

We feel that the most important lesson of all is that integration does work and it works well. It is difficult to write down the rewards of the program. There is not a column in statistical or quarterly reports for the emotional benefits. There are occasional problems (usually financial) and creative planning methods need to be found. However, if you strip the program down to its true essence you will see that there is no other way to go. Senior citizens with mental retardation and other developmental disabilities are full-fledged citizens. They deserve what everyone else is entitled to, including the right to make their own choices and dignity in their old age.



Middletown Center Project

Jane Rylander¹

Case Abstract: This case study describes a number of approaches for developing a seniors program in conjunction with a local senior center in Middletown, Ohio. The project experienced a range of growing pains, including rejection by center members, problems with transportation, and the need to teach socially appropriate "survival skills." It was found that the effort produced some positive results, such as favorable press, getting involved in volunteer activities, and getting a steady allocation of funds from the local developmental disabilities authority.

Introduction

The Middletown Center is located in Middletown, Ohio, a small community of some 46,000 persons in southwestern Ohio.

The Middletown Center is operated by the Butler County Board of Mental Retardation and Developmental Disabilities. It is one of three adult workshops established to meet a need of aging individuals (who are 55 years of age and older) who because of age, medical conditions, decreased stamina, and interest can not or do not want to work. The seniors program at the Middletown Center is modeled after another program which began in the 1970s as an "alternative to work" program.

At the time, the Middletown Center had an enrollment of 120 participants: eight were 55 years of age or older. However, the agency did not have services ready until the participants were medically unable to participate. At that time, several counties in Ohio had begun to recognize that many elderly individuals with developmental disabilities wished to participate in the same type of leisure and recreational activities as their "normal" counterparts. Thus, the agency set out to develop more appropriate programs for its service recipients with developmental disabilities.

Project Description

Prior to creating this program, the Middletown Center had an enrollment of 120 service recipients. Eight of these individuals were 55 years of age or older. In order to gain a clear understanding of these individuals' needs, a senior services evaluation was developed which contained basic information on their medical status; a summary of their strengths in the areas of daily living, academics, mobility, social interactions, communication, and vocation; and an interest inventory. The results were presented at the annual program planing meeting.

From our assessment we found that the agency needed to set up a program that would facilitate retirement and a broader use of generic aging network activities and resources, including our community senior center. Thus, we began a process to set up such a program. We started with a basic outline of what the program would attempt to address. Each of our older adults was asked if he/she would be interested in participating in the program. Based on the information obtained, the interdisciplinary team made the decision of how to tailor a program to address the needs of our aging service recipients with developmental disabilities.

There were some stumbling blocks which occurred over the course of the program.

Transportation for instance, was a big issue.

The Board's programs had access to yellow school buses which could be used for field trips in the community. However, the Board required two weeks advanced notice. Similarly, the city of Middletown had a public transit system which was appropriate for travel within the city limits; however, its buses were not wheel-chair accessible.



Correspondence should be addressed to Jane Rylander, Instructor and Project Coordinator, Middletown Center Adult Services, Butler County Board of Mental Retardation and Developmental Disabilities, 1520 14th Avenue, Middletown, OH 45044.

The lack of adequate staff was another problem. For instance, in order to take small groups into the community, not only was staff coverage for the group needed, but also staff coverage for those individuals who did not go on the trip. We tried to use volunteers, however, this too was unsuccessful.

Perhaps the most frustrating obstacle to the success of this program was the unwillingness of the elderly "normal" population to accept the participants with developmental disabilities as their peers. Not only were some of the service recipients resentful and uncomfortable with having individuals with developmental disabilities at the agency, there were also those individuals who looked upon these seniors as children whom they needed to "take care of" or poor souls to whom they should give things.

Throughout this integrative process, my goal was to teach the seniors with developmental disabilities acceptable social behavior and how to become more independent while using community amenities.

To resolve these situations, I gave two presentations at the senior citizens center. My goal was to help the members to interact more comfortably and more effectively with seniors with developmental disabilities. The presentations were given to the membership of the center during a weekly social program time. The first presentation was aimed at giving the membership a "bird's eye" or overview of mental retardation and developmental disabilities. This program was accompanied with a videotape of the various types of activities which these elderly individuals with developmental disabilities enjoyed. The second presentation concentrated on how to communicate effectively with individuals with speech handicaps.

To resolve the transportation issue, I applied for a transportation grant, which is still pending final approval. The problem of adequate staffing, and volunteers, however, have yet to be resolved. Although we have had several volunteers, we have not been able to secure them for regularly scheduled activities. However, I recently established a volunteer program among

the elderly seniors with mental retardation. Two of these seniors are volunteering at a nursing and retirement center, one folds towals in the laundry and the other holds and feeds tables in the Day Care Center which is run by the retirement center for children of the agency's employees.

This venture has generated a lot of positive effects. The program was featured in the local newspaper which ran a full-page, feature article on the seniors program. This article gave the program more exposure and hopefully increased the public's awareness of the needs of the population of elderly individuals with mental retardation.

The retirement center welcomed the skills and presence of the seniors in the community. These positive effects, I feel, have increased the seniors confidence and self-esteem as well as given them the opportunity to help others. The seniors in the program regularly participate in cooking activities, car washes and bazaars in order to raise money for outings.

The cost for this project has averaged \$500 - \$1000 dollars per year for supplies. The money for the program is rendered out of the Butler County Board of Mental Retardation Adult Services' budget. The Board's mission for the future is to achieve community inclusion for all of the individuals it serves. With this project, we believe that the Board is headed toward this goal.

Lessons Learned

The project has been successful, however, it has taken six years to get where we are now, and there is still much more that needs to be done. The lessons learned along the way are as follows:

Small groups of one or two individuals with disabilities in community activities are preferred.

Many program administrators fear that if they are "flooded" with too many new participants at one time, the "regular" participants will stop coming.



Public awareness is essential.

Most people are not against the integration of seniors with developmental disabilities, however, they do not have the information they need to accept these seniors into generic senior programs.

Securing adequate staffing via paid staff or volunteers is necessary for the success of any venture.

Generic senior service administrators are much more willing to allow integration to take place if adequate staffing is provided.

Creativity in the presentation of a project is essential for the project's success.

By verbalizing how seniors with mental retardation/developmental disabilities are as engaging as others seniors, senior center participants have little difficulty allowing them to participate.

Involving the mainstream of society or "normal" aged counterparts in a project results in an easier integration and inclusive transition.

By involving as many community residents and agencies as possible, the seniors with mental retardation have many more options for programming available to them as well as greater chances for developing more friendships.

Parting Comments

In summary, I have seen marvelous results from the establishment of this program for the elderly population with mental retardation/developmental disabilities. I have seen significant personality changes both in these individuals as well as the "normal" population. Although we

still have a long journey ahead, there is an abundance of hope for continued success in community inclusion for the elderly population with mental retardation/developmental disabilities.

I see the need for research and study of management and support for the elderly population with mental retardation/developmental disabilities who also suffer from dementia or Alzheimer's disease. The problem of these diseases become more evident as this population ages. Recently, I made a proposal to the local senior citizens center to lease space in order to establish the center as a home-base for our program (as a more appropriate alternative to the workshop setting). If accepted, the seniors would be able to socialize regularly in an integrated setting with their "normal" aged counterparts.

My "words of wisdom" to others are to persevere, cooperate, be creative and have a positive smile (even in the face of opposition). Providers working with this population need to be able to work effectively within their community to meet the needs of the population of individuals with disabilities. We are charged with the responsibility of assisting others to learn more about the similarities of individuals with disabilities: handicaps should be deemphasized. The key to success in integration is to seek community settings which pro-vide age appropriate activities and allow for the "blending" of individuals with disabilities within the mainstream. In order to achieve this goal, seeking senior volunteer companions to take the seniors with disabilities out to various community functions would likely result in a successful integrative "blending". The changes you will see may take time but they will be worth the wait.



Site Program

Adult day services -- commonly referred to as social model day care -- provide a range of supportive services to needy elderly or chronically impaired persons. Generally, the focus is on aiding the family which provides care 24 hours a day. In a sense, these programs provide respite for family members who may work, have other responsibilities, or seek time off from caregiving for vacations, medical appointments, and other personal business. However, such programs have recently become more focal points for supportive services which are also directed toward the individual placed within them. In many states, such programs are similar to day activity or habilitation programs that are provided to younger age people with developmental disabilities who do not qualify for a work-oriented program or whose complexity or severity of disability requires that they spend a period in habilitative care prior to moving on to another type of program.

Such programs often offer a range of activities that for seniors with a developmental disability are equated with varied retirement activities, particularly for those seniors who need a more structured site the offerings of a senior center or who may have retired from workshop activities. Many of the examples of senior programs we received fell into this service category.

The types of activities offered and the manner in which the programs were operated varied broadly as one can see from reading the following case studies. Much of this variation can be attributed to local program practices or state policies. We found a variety of approaches ranging from those that were set up to be the senior adult day care resource for their community (and thus open to all seniors irrespective of type of impairment), to those that were set up specifically as community retirement activity programs for seniors with developmental disabilities.

The lessons learned? One major finding was that programs such as these can be run at a relatively low cost. Another was that the approaches taken within the programs can be varied and flexible, depending upon the types of seniors being served. Such programs, when operated by a disability agency, can also become a resource for the greater community, particularly among elderly individuals living at home who have age-associated impairments. Many have broken from the model of traditional social model day care and have become innovative senior activity center environments, albeit with a more explicit purpose -- providing a warm, comfortable, but stimulating day setting for people with like needs.

Adult Dynamics Day Program

Bruce D. Hughes and Julie Hammond¹

Case Abstract: This case study describes a project undertaken in Corning, New York in which a social model day care program was expanded to include a number of older adults with developmental disabilities. The program developed a process for working with local agencies to facilitate referrals and interprogram cooperation. The program operator found that a group interaction approach to activity programming worked to their advantage in meeting the program's goals.

Introduction

In 1987, Steuben County's Institute for Human Services conducted a needs assessment regarding service gaps within the county. The lack of social model adult day care programs for the frail elderly was identified as a major concern. Pathways, a provider within the county, submitted a Needs Response Grant application to the Southeastern Steuben County United Way and was awarded a grant that provided funds for starting up an adult day care program. Thus, in mid-1988 Pathways began operating Steuben County's only social adult day care program.

Initially, the program -- titled Adult Dynamics -- served only frail elderly individuals from Steuben County. However, during the fall of 1988, Pathways was awarded additional funding through a demonstration grant administered by the state's developmental disabilities agency. These funds were also to be used to enhance the operation of the Adult Dynamics program and to permit Pathways to expand the scope of its adult day care program to serve elderly persons with developmental disabilities living in various community programs.

In 1987, New York State's Long-Term Care Policy Coordinating Council (a gubernatorial workgroup) offered its recommendations in a report titled *The State's Long-Term Care Service Continuum*. One recommendation was that agencies currently providing adult day services to persons with one type of impairment or disability (for example, elderly, mentally ill, developmentally disabled) should consider expanding their client base by also serving individuals of comparable needs, but with other types of dis-

abilities. It was reasoned that existing day service providers already have the administrative structure in place, have demonstrated the ability to operate programs within a regulatory environment, and thus could accommodate persons with similar functional needs (albeit differing diagnoses). Also, the Council concluded that there are inherent advantages to integrating individuals from groups with various disabilities from the standpoint of personal growth and efficiency of operation.

This case study describes the operation of this senior day services program and how Pathways, Inc., through the Adult Dynamics program, worked to implement the recommendation of the Council's report. The project served Steuben County on New York State's Southern Tier. The Adult Dynamics program is situated in Corning, a small community of 13,000 persons and the major town within the county.

Project Description

The downtown Corning, New York program site serves up to 18 persons on a five day per week basis in attractive facilities rented from the Salvation Army. The program has access to two activity spaces, the kitchen and dining area, lavatories, and a small staff office. At any given time, 6 or more of the program participants may be a senior with mental retardation.

Beginning in 1989, older adults with developmental disabilities were integrated with other older individuals who had age-associated impairments in a structured program. The main function of this program was to facilitate social-



Correspondence should be addressed to: Bruce D. Hughes, Ph.D., Executive Director, or Julie Hammond, Program Director, Pathways, Inc., R.D.#2, Box 170, Coming, NY 14830.

ly appropriate interpersonal skills in a relaxed, yet stimulating environment. Among the services offered were social group activities (we used interactive group games as a principal activity), personal counseling, nutritious meals, community outings and health checks (such as blood pressure monitoring and glaucoma testing). Our goal was the increased frequency and richer content of social interaction and participation.

The key people involved in the initial start up and ongoing implementation of the integrated social adult day care program included representatives from the County's Office for the Aging and Department of Social Services; United Way, Steuben County Institute for Human Services, the regional State Developmental Disabilities Service Office, and Pathways. Other vital players in the process were the program participants and their families.

Step 1 -- getting out information about the program to community agencies to obtain referrals.

Thus, the first phase involved expanding the client base of the Adult Dynamics program. We undertook a process of informing area agencies of the availability of the program and requested referrals of older persons with developmental disability that would be interested and appropriate for our program. This initial step led to some noteworthy challenges that we found had to be overcome in order to get started (we already had a clientele of frail elderly persons as well as some persons with other types of chronic impairments).

One of these challenges occurred in the Intake and Referral Process when the Adult Dynamics program director was trying to identify individuals who would benefit by being integrated into a seniors program for individuals who did not have mental retardation or a developmental disability. In order to accomplish this task, she observed elderly individuals who were participating in the Pathways Day Treatment Program. A meeting was held with the Pathways Day Treatment Program staff to discuss the program format and to reach an agreement regarding the admission of five individuals who

had been referred to Adult Dynamics. The Pathways Day Treatment Program staff then notified the family caregivers and the residential staff (at the homes where these five were living) of their recommendations to begin the referral process.

The first roadblock occurred during this phase of development when the residential staff expressed concern regarding what they considered the lack of active programming within the Adult Dynamics program. The residential staff involved were very committed to facilitating the growth and development of skills which would lead to greater independence for the individuals who were being considered for the program -that is, "active programming." The residential staff were concerned that the program would, in reality, resemble the stereotype of a nursing home dayroom where individuals usually slept and were cared for by staff rather than encouraged to engage in activities and function independently.

To resolve this obstacle, a meeting was arranged with the residential and other treatment team members to clarify the format and nature of a social adult day care program. This meeting went smoothly and the staff left with a positive attitude regarding these individuals' participation in an active recreation/leisure program. Also, the staff were invited to visit Adult Dynamics -- a few at a time -- to observe the format and participant interaction. We found it necessary to go through this process with two other treatment teams who expressed similar concerns regarding active programming.

After several individuals began to attend the program, the residential staff were able to observe the positive effects of goal-free programming. Since then, we have enjoyed a very positive working relationship with the family care and residential staff members. In turn, they have observed many of the benefits that social adult day care has had in the individuals' home environment.

Step 2 -- adapting our program to the needs of the individuals referred and aiding them adjust to the program.



A second challenge occurred during the transitioning of individuals with mental retardation and developmental disabilities into the Adult Dynamics program. This process began when the program director observed and interacted with each person in his/her own day program. Data were gathered to clarify each individual's level of game skills, interests, hobbies, social skills, medical needs, physical and/or medical limitations and their daily living skills. The individual was then invited to come as a guest to visit Adult Dynamics during a social time, such as during a coffee break or lunch.

The nature of the program was explained to the senior and a day and time for a meeting was set. During the time between this initial contact and the actual visit, the current day staff members were available to answer any questions the senior might have. The staff were also available to express support for this first visit. In some cases (as per the treatment team's request), a full visit with the senior to ensure his/her willingness to attend the outing and to assure the senior of the team member's support was arranged.

Prior to the initial visit, the participants of the Adult Dynamics program were notified that a visitor was coming, and told of the purpose of the visit. The staff then asked the participants to help make the visitor feel welcome, to explain the program to him/her, and to sit with him/her during lunch. A day program staff member would usually accompany the visitor to help alleviate any anxiety or nervousness the visitor might be feeling. Prior to the visitor's departure, the Adult Dynamics staff would ask the visitor if he/she had enjoyed the visit and if he/she would like to return for a half-day visit.

The Adult Dynamics program director would then contact the day program and residential staff to discuss the individual's visit and how the individual felt about the program. If he/she felt positively about the program, a second visit would be scheduled. The day program staff would transport the individual to Adult Dynamics and depart shortly thereafter (providing the visitor was comfortable with this plan).

The activities and grouping scheduled for this day would coincide with the visitor's interests and ability level.

As on the first visit, other participants would take control of facilitating the visitor's sense of acceptance with entering the flow of the program activities. This flexibility within a social adult day care program afforded easy scheduling and allowed the visitor to take part in activities he/she chose and which fell within his/her interests and ability level. As we used group games as a means of facilitating interaction and skills, we would try to match the game to the individual's skill level. For example, an individual who has limited reading ability but has "number" skills might not feel comfortable participating in "Wheel of Fortune" or "Sorry" but may feel comfortable participating in "Yahtzee," "Backgammon" or "Canasta."

Following this second visit, the individual would be asked how he/she enjoyed the program and if he/she wished to return. The residential and day program staff would in turn discuss the visit. If the response was positive, then a treatment team meeting would be scheduled. During the treatment team meeting, the individual would be asked if he/she would like to attend the Adult Dynamics program on a part-time basis. If the response was positive, then the team would make a decision regarding the frequency of attendance (taking into consideration the individual's ability to adjust to change). If the response was uncertain, then additional visits were arranged in accordance with the individual's wishes.

Some individuals began on a three half-day per week schedule while others began on a one full-day per week schedule. As each individual's adjustment seemed secure, a subsequent treatment team meeting would be held to discuss increasing the frequency of attendance at Adult Dynamics and to determine if the participant wished to attend more often.

Our process of transitioning two groups (one with mental retardation and the other with other types of disabilities) was based on matching levels of ability and interests rather than on back-



grounds. A number of people with mental retardation were able to relate comfortably and appropriately with those who did not have mental retardation with very little assistance or training. All of the participants interacted together during a number of large group activities, regardless of their ability. Those individuals who lacked game skills were scheduled for one activity each day with staff to assist them in acquiring additional skills. In addition, those individuals who demonstrated needs with respect to social interaction, acceptance and understanding of others were invited to participate in a weekly session which used discussion and role playing to facilitate better social interaction.

For those individuals with mental retardation, the greatest need was in improving their interaction skills. Most of these individuals were very social in nature; they demonstrated a desire to help others through useful activities and they were accepting in their attitudes toward others with handicaps. The areas which needed to be enhanced were their social interaction skills and their knowledge with respect to topics of interest; for example, learning how to begin and continue a conversation, learning how to ask informational questions thus learning more about the other person, learning to identify feelings and opinions, developing an active selfinitiating mind-set as opposed to a passive, "receiver-only" mind-set, and learning which topics of conversation should be avoided.

The use of discussion groups and role playing, as carried out within a social environment, strengthened these skills in very dramatic and positive ways. This is not to say that every participant is now "the perfect socialite." However, we have watched people develop a greater self-identity and we have seen people who were withdrawn and unsure of themselves develop confidence and humor and form positive friendships.

Step 3 -- enabling the participants to chose from the options for daily activities open to them.

A third challenge was improving the game skills that would enable the individual with

mental retardation to improve his/her mental ability and socialization skills and have a greater range of choices for independent activities.

If one of the seniors was having difficulty learning a particular game, the staff developed new, simplified games to train the individual in acquiring the specific skills that were needed to play the original game successfully. For example, an individual learning "rummy" may learn two games before combining them to play "rummy:" a card game where only three or more of a given matching card can be played, (e.g., 3 Aces, 3 Fives, 3 Jacks); a card game where only 3 or more consecutive cards within the same suit can be played for points (e.g., 3, 4, 5 of Hearts; or a Queen, King, Ace of Diamonds).

Individuals who have difficulty with a game like "Yahtzee," for instance, may first learn several other games that staff invented to develop the skills needed to play "Yahtzee" (e.g., 1, 2, 3 dice involves each person taking a turn and having 3 rolls of the dice to roll as many Ones as possible. The next turn each person rolls as many Twos as possible). This pattern shows the concept of how points are scored and helps people learn to recognize the patterns of dots on the dice. For instance, each person rolls the dice 3 times to get a small-straight. During the next turn, each person rolls to get a large straight.

The same concept has been applied to "Bingo" where special cards have been developed that use letters, and other cards that use numbers, to help people learn how to play "Bingo." For example, a person who knows only numbers 1 through 10 can learn to identify "45" by listening and hearing "forty-five" and then finding the numbers 4 and 5 on the card. We have also used cards and the concept of placing a chip on a square to enhance the participants' ability to listen attentively. Likewise, the card game Uno can be divided into two games where people match only numbers or colors. Hence, we have cards with pictures, symbols and shapes.

Other than simplifying games to train the person in the skills needed to participate inde-



pendently in the original game, we have also developed some games which can be enjoyed by all. For example, one of the most popular games at Adult Dynamics is "B-C Dice." This game is similar to "Yahtzee," however, instead of being limited to rolling only one large-straight or full-house per game, each combination is given a numerical value and may be rolled as many times as desired. The player then decides what combination he/she will "go for" after the first roll which makes score keeping much easier and offers the player more opportunity for decision making.

We have also developed our own game boards which provide an additional variety of activities to train participants with matching numbers, identifying dice dot patterns and moving game pieces in sequence. The participants enjoy each game -- whether the original, simplified, or modified -- and view the game as a fun activity rather than as a vehicle for learning (which it really is). Integration occurs on all levels and is usually "activity specific." For example, one participant, who has poor reading skills, may not join in a game with another participant, who has excellent reading skills. while playing "Monopoly" or "Wheel of Fortune." However, they both may enjoy one another's company playing "Uno," "Backgammon" or "Rummy."

Lessons Learned

Programs such as these can be run for a relatively low cost.

The costs of the project are low when compared to medical model programs. The per diem cost has been approximately \$25 to \$30, compared to the Medicaid day treatment program per diem costs of approximately \$70. A combination of community funding, through the United Way, private payments from community participants, and state grant funds, has been necessary as there has not been enough income generated from the relatively small number of program participants (8-10) during the first two years. Having 15-18 participants during the third year has led to more funding.

The hidden costs for program operation have been in the areas of transportation, liability insurance and administration and overhead. The liability insurance was simply much higher than anticipated, and there was no money available to reimburse the agency for the administration, supervision and business/personnel office expenses.

Retirement programs can be run with a great deal of flexibility

We have found that the format of the social adult day care program lends itself to a great deal of flexibility and creativity. This flexibility makes it possible for a great diversity of needs and interests to be addressed within one program site. It also allows for individuals from a variety of backgrounds to join together on common ground and benefit from one another's friendship.

Transportation can be a problem

A barrier has been transporting program participants. Due to the inadequate funding to pay for a local transportation agency to transport all of the participants, some participants have been transported by family members, some by vehicles owned and operated by state-operated residences, and some by Pathways' staff. While these methods of transportation have been meeting the need at this time, they are not satisfactory solutions in the long-term because of a need for wheelchair accessible vehicles.

Parting Comments

Our experience has shown us that such a program can be extremely cost-effective in at least two very important areas: First, some frail elderly individuals have been able to remain in their family homes for much longer than if they had not received our services; and second, -- for those participants who had previously been attending day treatment programs -- although the cost is approximately half the former per diem rate, each individual appears to have maintained or shown improvement in his/her overall functioning.



Casebook of Program Ideas in Aging and Developmental Disabilities

Pathways' experience has demonstrated that the Governor's Council recommendations of 1987 have been appropriate as they relate to the idea that existing agencies currently providing adult day programs for one group could easily be expanded to include a more diverse population. The state's policy to allow elderly individuals with mental retardation or developmental disabilities, who reside in intermediate care facilities, to participate in social model rather than medical model programs, cannot only be cost-effective, but can be advantageous also to the overall well-being of the individual participants.

Recommendations for other administrators who wish to start up a similar program as ours are:

- To hold discussions with potential referral agency staff regarding the specific purpose and goals of the program as those individuals who are in the position to make referrals must clearly understand the function of the social adult day care concept.
- Agencies that are considering starting an integrated social adult day care program should involve representatives from other agencies in the early stages of development, including the area agency on aging, the local public welfare/social services office, developmental disabilities agencies, hospitals, the state developmental disabilities agency and mental health service providers.
- The process of obtaining a joint team consensus regarding the decision to increase an individual's attendance at the program can be more efficient if a specific transition method is in place prior to the initial treatment team meeting. With a specific transitional plan in place, a team meeting can be held to determine the individual's readiness to increase the time spent at the adult day care program. With such a plan in place,

communication among the staff of the adult day care program, the former day program, the residential program, and the participant can work toward everyone's interest.

The integration of persons with mental retardation and developmental disabilities with frail elderly persons in a social model adult day care program has been a very successful experience for Pathways, the program participants, and their families. We feel very positive about the social skills development and growth we have observed and we strongly support the concept of integration.

We have learned that pre-planning -- which involves multiple potential constituents -- will lead to a greater likelihood of success. We have also determined that a slow, gradual process of involvement or transition into the integrated environment minimizes stress and helps to ensure positive results for the seniors.

In recent years, the integration of individuals with developmental disabilities into existing community programs has appropriately become a popular goal for service providers. Pathways' experience with integrating seniors with mental retardation and developmental disabilities into social adult day care programming has been one of the most successful examples of this philosophy. We have discovered that as individuals grow older, their needs become more similar.

Agencies that are already experienced in the provision of services to adults and specifically to elderly persons with disabilities, have a distinct advantage in the establishment of integrated social adult day care programs. These agencies are already prepared to meet the needs of persons with disabilities. The next major task is finding ways to encourage the people who have and do not have disabilities to interact more. As we have shown, interaction has been more of a technical problem for staff than a problem for the individuals served.



Cattaraugus Outreach Project

John R. Searles¹

Case Abstract: This case study describes the effort of an agency in rural upstate New York to create an outreach process to locate older people with developmental disabilities for the county's social model day care programs. The project -- originally funded under a special development grant -- was able to locate a significant number of previously unknown seniors. The project showed that older adults with developmental disabilities can be readily integrated into an aging network program and that in rural area, such cooperative programs can be very useful.

Introduction

Like the elderly population in general, the number of older people with developmental disabilities is growing. In New York, as in other states, the two systems serving seniors and other seniors with developmental disabilities have been separate and independent. The developmental disabilities system tends to emphasize the young and working age adults, while the aging network concentrates on a wide rage of needs of the overall older population.

The elderly population is served by a system of agencies which uses age 60 as an eligibility criterion for services. At the local level of this network is the area agency of aging (AAA). A separate system has evolved to serve the population with developmental disabilities, regardless of age. This system differs from the aging network in that there is no formal definition of old age. Developmental disabilities agencies function at the local level to provide services and oversee the well-being of persons with developmental disabilities in their areas. These two systems could, and should, cooperate with one another in the provision of services to the older population of adults with developmental disabilities.

To test this notion, this project came about in 1987 when the New York State Developmental Disabilities Planning Council awarded a grant to test the feasibility of integrating older individuals with developmental disabilities into generic aging network services. This case study describes the integration experiences by our rural county-based AAA which was awarded a grant to be implemented at two social model adult day

care centers. The project was located in Cattaraugus County, a large rural county with a population of 84,000 located in western New York State.

Project Description

The goals of this project were two-fold:

- The Cattaraugus Outreach Project sought to identify, locate and disseminate information about existing aging network services to as many older adults with developmental disabilities as possible within the county.
- A select group of older adults with developmental disabilities were to be integrated into an adult day care setting and later involved in senior citizen clubs, congregate nutrition sites and other programs. The adult day care setting was selected for the initial integration simply because the array of services available through the aging network were provided, or could be arranged, at these locations.

Both formal and informal service providers were involved in identifying these older adults. The resources of the developmental disabilities system -- specifically the J.N. Adam DDSO, our regional state developmental services office, and the Cattaraugus Rehabilitation Center -- were tapped into early in the project. Throughout the project, day care staff were available for public speaking engagements, staff training and inservices.

Other agencies, such as the United Cerebral Palsy Association, National Multiple Sclerosis



Correspondence should be addressed to John R. Searles, M.S., Director, Cattaraugus County Department of the Aging, 1701 Lincoln Avenue, Suite 7610, Olean, New York 14750-1101.

Society and the Association for Crippled Children/Adults were surveyed to assist in the identification of older adults with developmental disabilities. To avoid any problems associated with the release of confidential information, each agency surveyed was provided with a stamped envelope which contained a number of flyers describing available services, a stamped return post card and a cover letter. Agencies were asked to provide the project with the number of older adults with developmental disabilities they served. Envelopes were then forwarded to them, and these agencies addressed and mailed the packets. If an individual was interested in the services described they contacted the project. This method was also used with all agencies in the developmental disability system.

Considerable efforts were made to identify those individuals already receiving services from the County Department of the Aging. Attention was focused primarily upon the congregate/ home-delivered meal and outreach services. Staff of the Department were asked to compile a list of individuals they felt may potentially, have developmental disabilities. To aid them in the process, a special assessment and screening instrument was used. This instrument provided Department staff with criteria useful in identifying individuals who may have a developmental disability. Once identified, a referral was made to the project. Follow-up was then done by project staff. Sixteen individuals were identified as receiving services from this network.

Members of the clergy were also involved. Project staff compiled a list of churches in the county. Each pastor was mailed a letter explaining the project, its goals and asking for their cooperation in disseminating information. A supply of informational flyers accompanied this letter. Letters were mailed to over one hundred fifty churches, which resulted in two direct referrals to the project. This effort was viewed as having long-range impact in that the clergy were made aware of the services available and would refer individuals as the need arose. A total of 42 individuals were identified through these efforts. In addition, seven individuals were referred by the Health Department, seven by the Association for Retarded Citizens, six by the

state developmental disabilities office, two by various mental health agencies, one was self-referred and another was a referral from a human service agency.

Twenty-three of the people identified by the project had a primary diagnosis of mild to moderate mental retardation. The one remaining individual had a diagnosis of profound mental retardation. Five individuals had a primary diagnosis of cerebral palsy, five had epilepsy and another four individuals had multiple sclerosis. Four individuals had a dual developmental disabilities/psychiatric diagnosis. Three of these dually diagnosed individuals had a diagnosis of mental retardation/schizophrenia and the fourth cerebral palsy/schizophrenia.

Those individuals identified included some individuals who were under the age of 60. Due to impairment in their activities of daily living (ADLs) and given their case histories, they were deemed appropriate for aging network services. One woman, under the age of 60 who had epilepsy, had spent all of her life in either a hospital or nursing home, and easily adapted to the pace of adult day care activities. Interest in aging network services among those identified varied with need. Thirty-two were interested in receiving congregate nutrition services and associated nutrition education services. This interest was expected as the majority of referrals to the project came from these program components. Of those individuals identified, nine were interested in nursing services, eight in home delivered meals, eight in a senior citizen discount program, seven in information and referral, four in senior citizen club activities, two in outreach services, and one in financial counseling/money management.

With regard to our targeted efforts to include some of these older adults within the Linwood Center in Jamestown (the county's main social model adult day care site) and our other setting in Salamanca, we were able to integrate 23 of the adults. These centers provide five basic services to participants: transportation, nutrition, case management, personal care and structured activities.



In preparing for the integration, staff training was provided by both project and DDSO staff. This training was informational in nature and stressed the similarity between those adults with a developmental disabilities and the elderly population already served by the centers. The adults with developmental disabilities were senior citizens with some limitations in their ADLs. The approach used at these centers was complete integration with the existing clientele. There were no major changes in programming. Existing clients were not given any information on either developmental disabilities or the new participants, as per center policy. The adults with a developmental disabilities were integrated as they were referred.

Case managers were assigned to each senior as the senior entered the center. It was the responsibility of these case managers to develop an individualized case plan which challenged the seniors without frustrating them. The plan was written in conjunction with both the senior and the caregiver. This plan included such items as sign recognition (e.g., men's versus women's bathrooms, stop signs, etc.), help starting conversations, development of alternative leisure time activities, and gradual involvement for some in senior citizen group activities and congregate nutrition sites. All of the seniors were encouraged to try new activities, yet participation in activities was never forced or required. Instead, the onus was on staff to develop programs around the participant's interests.

Early in the project, we realized that some of the seniors integrated into adult day care would probably not progress beyond this level of service. These individuals were content to accept the slower paced age-appropriate programming of the centers. In these cases integration was considered successful if these seniors did not regress. Six seniors were included in this form of integration. The older adults with developmental disabilities were encouraged to practice skills which were directly transferable to other settings. One senior assumed responsibility for wrapping silverware each day. A second monitored another senior who choked frequently and was responsible for calling staff as needed. Each person was given some responsibility and allowed to find his/her niche. The day care setting created an environment in which hidden talents blossomed. In some cases these people functioned at or above their peer group for the first time in their lives.

In working with senior citizen groups, project staff spent a great deal of time stressing the similarity between those seniors with a developmental disabilities and frail senior citizens to help overcome the stigma of mental retardation that many senior citizens experienced. Initially, seniors with a high degree of skill capabilities were chosen for integration. Careful arrangements were made so that cues provided by staff were kept to a minimum.

What were some of the outcomes? Four of the seniors got involved, on a limited basis, in senior citizen club activities at a different location in Olean. Others were encouraged and eventually transitioned from the day care setting to other activities of their interest and choosing.

Lessons Learned

Integration can be a positive experience for all involved, but it is not categorically appropriate for all people.

In integrating people with developmental disabilities, project staff focused upon the individuals' functional limitations in ADLs. rather than diagnoses. It is more important to know if someone is continent of howel and bladder than it is to know if someone has mental retardation. Generally, the greater the degree of impairment in ADLs, the more structured the environment needs to be for integration. Conversely, for seniors with minimal impairments, a social day care setting may offer a too structured program and referral to alternative activities may need to be sought. We also found that social day was a good place to learn socialization skills that could then be used to enter the world of senior clubs or activity centers.

To be successful, integration requires both willingness and cooperation on the part of both the aging and developmental disabilities systems.



We encountered some resistance from the local developmental disabilities providers which, although had not developed or were not providing retirement age programs, resented loos ag clientele to an outside agency. Thus, we were initially unable to get referrals from them. However, the intervention and facilitation of the state's regional developmental disabilities office, we worked out an arrangement for referrals and cooperation. Indeed, we were able to make some referrals to them of individuals who turned up in our outreach who would have been more appropriate for their services.

What helped also was the clear articulation of state policy that our two networks were to work together and that the focus of senior services was going to be on the aging network.

Parting Comments

Social model adult day care provides unique opportunities for integration. It can serve the needs of the senior with more functional limitations while also serving as a starting point for the integration of adults with greater functional skills. Our experiences proved to us that suc-

cessful integration of older individuals with developmental disabilities is a real possibility. Our project benefitted by being in a rural area where, although resources were limited, cooperation between agencies was excellent. However, we also learned that when integrating seniors with developmental disabilities each individual must be considered separately, realistically weighing the cost/benefits of intervention for both the individual and the program.

The time is ripe for cooperative efforts between the aging and developmental disability networks. Each system can enhance the other while serving the needs of each individual. To be successful, however, integration requires both the willingness and cooperation on the part of both systems. A significant step toward this integration effort was taken in January 1990 when representatives of the New York State Office for the Aging and the New York State Office of Mental Retardation and Developmental Disabilities signed a Memorandum of Understanding relative to older New Yorkers with developmental disabilities. This memorandum set the parameters in which cooperation between these two state agencies and their associated community agencies could occur. Such cooperation is essential if integration is to be successful.

Life Management Retirement Services

Lynnett F. Stucky-Mack and Anne Benjamin¹

Case Abstract: This case study describes the experiences of a small, non-profit organization in Lawrence, Kansas, which undertook a retirement program for seniors with developmental disabilities. The agency provides daily recreational/cultural/educational activities as determined by the members, including integrated events with persons in the community. In addition, 1-3 program days per month are offered to those individuals contemplating retirement to assist them in exploring their options and act as a transition period. It was found that the program is welcomed, but that initial misconceptions need to be overcome, and compensation to the seniors for loss of employment is advised.



Correspondence should be addressed to Lynnett F. Stucky-Mack, Director of Quality Assurance and Specialized Services Cottonwood, Inc., 2801 West 31st Street, Lawrence, KS 66046.

Introduction

In the service field, we are only beginning to address the needs of persons with mental retardation who are in their "golden years". Retirement is a relatively new idea in the provision of services to persons with developmental disabilities. Yet according to national demographic trends, the proportion of an individual's life spent in retirement is increasing. Additionally, experts in the field say there are at least 200,000 people over age 60 with mental retardation in the United States. In 1990, our agency responded to the need that is becoming apparent across the country; that is, to provide a culturally normative retirement experience for persons with mental retardation.

Cottonwood, Inc. is a private, not-for-profit agency located in Lawrence, Kansas, a community of some 53,000 people. It serves as the Community Mental Retardation Center, or lead agency, for Douglas and Jefferson counties in Kansas. The agency offers work services, residential, employment, retirement and support services to adults with developmental disabilities. It has experienced steady growth since its incorporation 20 years ago. One hundred fiftyseven individuals are currently served at Cottonwood, and the agency works in collaboration with other agencies and businesses locally and across the region. It is represented on the local transitional council and several boards for other service organizations. It works in cooperation with the local school district and provides training to enhance work skills of several students each year. The agency also maintains an agreement with the local vocational rehabilitation office in which a service fee is received for job coach hours. Life Management Retirement Services has benefitted directly from cooperative efforts with the City Parks and Recreation Department as well as with the Senior Service agency.

In March 1990, our agency's demographic report indicated that services were provided to a group of four seniors with mental retardation who were over the age of 65; five in the 60-64 age range, and fourteen between the ages of 50 and 59. We were serving several persons with

Down syndrome over the age of 35, one of whom had been diagnosed with apparent early manifestations of Alzheimer's disease. We also knew of a few un- or under-served people in the community. Three months after the program began, the demographic report showed eight individuals over the age of 65, six in the 60-64 age range and fifteen between the ages of 50 and 59.

In contrast with their nondisabled counterparts, many adults with mental retardation have not had the opportunity to spend their retirement focusing on life reflection and recreation. Prior to the new program, "retirement" may have been experienced as a lack of services. A senior with mental retardation was likely to remain in the work force until the services of a nursing home were required. Upon entering a nursing home, the individual may have continued to work parttime, or dropped out of the Cottonwood service system entirely. The individual would then have lost his/her only support system at this crucial transition point, and experienced extreme losses in areas of peer interaction, recreational activities, and emotional security. Because they required supervision or more intensive training to participate in the activities offered, many of these people lacked the resources to access generic semior services.

Determining a direction for service development involved making some decisions. We needed to create a discrete service and address these changing needs, providing for culturally normative retirement options.

Project Description

Our goal was to provide seniors with developmental disabilities the same kinds of retirement opportunities that are available to seniors without these disability factors. We were able to provide these opportunities with the help of the Kansas Planning Council for Developmental Disabilities Services. In April 1990, a request for proposals to provide "age appropriate day activities for aging persons with developmental disabilities" was sent out by the Kansas Planning Council for Developmental Disabilities



Services. We applied and were given a support grant. The grant monies were used to defray the initial start-up costs of the life management retirement program which began in September 1990.

This grant allowed Cottonwood not only to provide services to an immediate group, but also to provide for future informed choices regarding retirement services through the retirement readiness component. Inter-agency cooperation was a priority throughout the project and the grant proposal was supported by many key people, including the executive director of the local generic Senior Service agency, the executive director of a residential provider serving many older men with mental retardation, and the Special Populations Coordinator for the City Parks and Recreation Department.

Fourteen men and one woman have been served through Life Management Retirement Services during the first nine months of operation. Thirteen of the participants were over 55 years of age. One of the first referrals was a 38 year old individual who was diagnosed with Down syndrome and had symptoms consistent with Alzheimer's Disease. Another individual who was 51 years old, was referred because his team felt that he would be best served in the retirement program. Of those individuals diagnosed with mental retardation, there have been three diagnosed with borderline level of impairment (one adult had diabetes with this being the primary limiting factor); eight with mild; two with moderate; one with severe; and one with profound impairments. Mental illness was a secondary diagnosis for four participants. Twothirds of the referrals came from a communitybased residential program for men. This referral base may have created the low female:male ratio among the participants.

Our project included a retirement readiness component offered one-to-three program days per month to five women and four men during the first nine months. This service was provided to individuals who were 50 years of age and older, or 35 years of age and older if they had Down syndrome. Individuals were offered the opportunity to join the retirees one to three

times each month; however, they were not under any obligation to attend any of the program periods.

Retirement readiness participants get some knowledge of the retirement options available to them, so they can make informed decisions about their future. In the process, they create a peer support structure that will be in place should they choose to retire, and thus make their transition into retirement a smooth one.

The usual staff to senior ratio is 1:5, however, this ratio varies considerably depending on the activities scheduled for the day and the number of persons attending through the retirement readiness component. Staff providing Life Management services include a director (25% time) with 12 years of combined experience in the fields of gerontology and developmental disabilities services, a full-time social work coordinator, and a full-time direct contact staff person. Volunteers and a contracted nurse provide additional activity facilitation.

A lease agreement was arranged between Cottonwood and the City of Lawrence Parks and Recreation Department allowing inexpensive access to 1000 square feet in a city community building during the period of 8:30 a.m. to 4:00 p.m. The program had use of a kitchen, gymnasium, billiards area and access to a city park. During the afternoons, we shared the building with the "after school set," for whom the building served as a recreational hangout. It was also used by clubs and was the site for the monthly neighborhood association meeting. The building proved to be an ideal location for cooking, program activities and a starting point for nature hikes.

Health is a more important factor for older adults than for young and middle-aged persons. Thus the agency contracted with the Douglas County Visiting Nurses Association to provide two hours of nursing services each week for the life management program. The nurses, following the yearly curriculum guide, tied nutrition, exercise, safety, relaxation and education into the theme of the month. Program participants seemed to enjoy this, and looked forward to



each week's class.

A city-wide volunteer clearing house program, contacted by Cottonwood's Community Relations Development Department, paired us with a volunteer guitarist for a morning and afternoon of singing and group performances each week. The retirees have sung in a nursing home, retirement high-rise and a grade school. A university student, paid by the Kansas University Community Service Program, helped with individual program plans, community outings and interest assessments two-to-three times a week during the past two semesters. A retired woman from the neighborhood came in every week during the autumn months to lead an hour of crafts and group leisure. This tended to be educational in nature, and occasionally led to more in-depth study. For several weeks the participants worked on a miniature diorama before going to the University of Kansas Natural History Museum to study the dioramas there. Similarly, a miniature volcano experiment led us to local geologic features.

The program is self-directed in nature, and the people involved decide what their activities will be through monthly program meetings. In the meetings, participants indicated what activities they have enjoyed as well as which ones they would rather not do again. The group decided on several activities that were priorities in the upcoming month. Suggestions from staff usually tied in with the curriculum theme for that month, however many suggestions came from the participants and were not so directly connected. Self-direction is of paramount importance in our program, as it seems to be one of the defining factors of "retirement".

Lessons Learned

There is an apparent fear of "retirement," with potential retirees fearing that it will represent a loss of freedom, choices and mobility.

This fear was allayed, to some extent, through education. The program staff met with potential participants in their residence, work place, or elsewhere and explained the self-directed

nature of our program. Specific planned activities were discussed and possible future activities explored. We started with a small group of 8 participants the first week, and allowed word-of-mouth to do the rest. The program was fortunate to have a highly respected, vocal participant who soon recruited many friends. Within three months, we were serving 15 individuals, surpassing our annual goal of 12.

Money, which is often a barrier to retirement options, prohibited several individuals from quitting or cutting down in their work schedule. We offered flexibility in scheduling, and several participants were able to join the retirement group one or more half days each week and not lose all of their earnings. Flexibility in scheduling was particularly successful in overcoming many of the barriers, and having the administrative support to accommodate a myriad of scheduling needs was critical to our success.

Parental resistance is often a barrier to participation.

Some parents expressed reluctance to see their "child" as old enough to be retired; and some seemed to view any day service other than work as a step backward rather than "age appropriate." One parent commented, "Oh, I think John gets plenty of recreation and activities at home." Integration into the community was also not seen as a benefit for some parents, who questioned the safety and seemed concerned that it would be "too much" for their son or daughter. This resistance was overcome in some instances through the support from the case manager, an established and trusted point of contact. Case management support was followed up with education in the form of a letter or telephone conversation with program staff, and self-reported enjoyment from the son or daughter. Our flexibility allowed participation in either the retirement program or the retirement readiness component, joining the group just three times each month with no commitment to attend. Most of the individuals for whom this had been a barrier are in the program and some have even increased their scheduled attendance. The success, however, has been limited. One individual who seemed to enjoy the

program when attending is only able to join the group one time per month due to parental resistance.

Resistance within community programs can be overcome.

We did encounter some resistance when we were including ourselves in community events. Senior center staff expressed initial concern that their regular clientele were uncomfortable with clubs or classes being intruded upon by newcomers who may have been demanding, disruptive, or just would not fit in. Through numerous meetings with senior center staff, we have opted for a slower inclusion process in the more exclusive events, and increased exposure in larger group activities. Essentially, the people who already meet the group's criteria went immediately into the group if they so desired. Others joined with initial 1:1 staff support, and learned more about community norms by being in community "hangouts" that were not as exclusive, such as coffee shops and senior meal sites. When major events occurred at the generic senior center during program time, participants attended as desired. Program participants increasingly met general community expectations and gained acceptance at the senior center.

When mobility becomes a problem for older retirees, seek kelp from other agencies involved in their care.

During the colder months, we noticed that the strength of our oldest participants began to decline. In one instance, one older woman could no longer pull herself up or lift her leg to climb the steps into the van. Her stamina also decreased and she had great difficulty enjoying outings to museums and other local attractions. Through the intervention of the nursing facility in which she resided, she was assisted by restorative aids that helped her to rebuild her strength. Soon she required considerably less help to climb the steps into the van and a wheelchair was available for events which required a lot of walking.

Although administrative barriers can occur, they can be overcome.

Although there had been some internal resistance to reorganizing the agency's systems and resources to make accommodations for the new program, we did enjoy administrative support and the support of other departments improved as the seniors reported their successes. One particular difficulty was the admissions process; however, new systems were developed in an extended Admissions Committee meeting to the apparent satisfaction of all departments. The kick-off Open House event seemed especially effective in gaining the programs acceptance within the agency, and the individuals we served continued to be vocal about their activities and enjoyment of the program.

Parting Comments

The Life Management program is overall very cost-effective, with an average cost of approximately \$26 per day. This price is slightly over half the average cost of our work services program and is comparable with other programs in the agency. The benefits to the individuals certainly outweigh the costs, and the program is valued within the administration and governing body as a worthwhile service offering. Initially, the program was funded partially through a grant from the Kansas Planning Council on Developmental Disabilities Services in conjunction with the Kansas Department of Social and Rehabilitative Services. Current sources of funding include the Home and Community Based Waiver and county mill levy monies from both Douglas and Jefferson Counties.

The low cost is due in part to the reduced cost of the program space as well as staff diligence in finding inexpensive program supplies and making use of generous donations. Although the space is cost effective, there is a hidden cost factor involved as we are occasionally unable to use the facility and our wall hangings and materials have been damaged by vandals. The knowledge that items may be stolen or damaged has prevented us from purchasing some materials.

Our project expectations were to provide services to 8 to 13 people during the first year.



We actually provided services for a total of 15 persons. A greater number of people and a shorter time frame not only represented enrollment success, but signified the need for more retirement services within our community.

The grant also put into effect an integration policy requiring staff to offer participants two integrated events each week. The January to March program evaluation reported a goal of 30% program time per month in integrated activities which was achieved with an actual time of 34%. This means that participants spent one-third of their time with others, at least 60% of whom were outside of the special population or service field. Staff accompanied the participants for a smooth transition into community events. Eight people attended an 8-week music therapy class for seniors sponsored by the University of Kansas's Music Therapy Department. Fifteen Life Management participants attended a Russian Day celebration at the senior center. Several individuals regularly attended an exercise class and painting club later sponsored by the senior center as well.

Cottonwood, Inc. is accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF). The Life Management program anticipates meeting the requirements for CARF accreditation in Personal and Social Adjustment Services by the end of the first year. Perhaps due to this push for accreditation, staff avoided shortcuts and used CARF guidelines to set up the program. This push resulted in an organized annual curriculum guide with daily activity plans developed with consumer input, and a monthly pre-test and post-test. A list of community resources was developed and is helpful in facilitating inclusion in local daily events and special features. The safety committee, also part of the CARF guidelines, is chaired by the direct contact staff and is useful in keeping staff and participants aware of safety issues and precautions. Excellent training and documentation is also achieved by following the guidelines provided.

Our experiences have led us to make these suggestions.

- It might be helpful to access rental space with a twenty-four hour control clause. This rental space would allow staff to do interior decorating with easy chairs, coffee tables and rugs. While it is cost-effective and ideal in many ways, sharing the use of the building with so many other groups and functions does not permit redefining the atmosphere. We believe we could have created a superior place of relaxation through the minor redecoration mentioned above; however, this would have prohibited some of the other, concurrent uses of the space.
- Set up an annuity program to compensate workers for loss of employment and facilitate a retirement option. A front page article of The New York Times questioned whether or not sheltered workshops should provide for retirement and pay pensions. Until community employment options are universally available, it appears likely that many individuals will be in and out of sheltered work and would benefit from such an annuity plan. The loss for persons who worked the majority of their tenure before the initiation of the annuity plan will need to be addressed as well, to make a fair benefit package. The agency has recently revised client worker benefit policies to make them equal to staff's in areas of vacation and sick leave. A wellplanned retirement benefit seems a logical extension of the overall philosophy that prompted the above mentioned policy revisions.
- Produce a slide show to introduce a culturally normative retirement experience in pictures. Many of the people who receive Cottonwood services believe that retirement is synonymous with placement in a nursing home. Three of the people who are involved in Retirement Readiness seemed interested in their invitations to join Life Management until they heard the program was a retirement service. Staff used publicity to educate the potential Life Management participants about retirement options for adults with mental retardation.

As a new program, Life Management attract-



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ed front page coverage in the agency newsletter and special mention in the annual report by the president of the board. A meeting between the mayor and program participants was highlighted on the local evening news. A goal for the program staff is to continue using publicity as a way of educating the public, families and policy makers about the needs of the retired person with mental retardation and to make retirement another area of choice within the parameters of control for seniors. Education through publicity is an important goal because the issue of retirement for persons with mental retardation has received relatively scant attention by policy makers and service providers.

Our closing words of wisdom include using an accreditation outline whether your program is seeking accreditation or not, because well planned, quality services will prove to be beneficial for the participants. A second word of advice is to have retirement options include a shift from fixed day program participation to less regular, or individually tailored day program schedules. We recommend making your program schedule flexible to accommodate the

work and other needs of potential retirees. Some individuals may work less because of reduced stamina or motivation while investigating retirement options. As one Life Management participant said, "I go to work but I don't get tired, because I have Life Management now."

The Life Management Program attempted, on a daily basis, to provide seniors with the retirement experience that they want. The participants were vocal in their choice of individual program plan (IPP) objectives and in evaluating and directing the agenda through monthly meetings. The success of IMP and program goals support the choice framework of retirement services. In addition, the number of program participants surpassed the annual goal and individuals continued to increase their time in the retirement program. This push, combined with a high attendance record, demonstrated the need for retirement services. A flexible schedule is an important factor in the success of the program. Educating the public about the need for retirement benefits to facilitate a culturally normal retirement experience is a long-term challenge for staff members.

PEOPLE, Inc.'s Adult Day Care Program

Ellen M. Lewis and Susan Matthews¹

Case Abstract: This case study describes a social model day program in Buffalo, New York which was designed to provide day services for older adults with developmental disabilities. The project drew its activities from the types of activities that were found in community senior centers. As in other similar programs, resistance was noted among other developmental disabilities providers who were unsure about what a retirement age program provided and were concerned about how programming requirements could be met by the operators.

Introduction

PEOPLE, Inc. is a private, not-for-profit organization which provides services to individuals with developmental disabilities and

their families. The main administrative offices are located in Buffalo, New York (a metropolitan area of some half million population). Services are provided throughout a number of western New York counties including Erie,



Correspondence should be addressed to Ellen M. Lewis, Director of Project Development or Susan Matthews, Program Manager, PEOPLE, Inc., 3909 Genesee Street, Cheektowaga, NY 14225.

Niagara, Orleans, Genesee, Cattaraugus and Chautauqua. Incorporated in 1970 as "Services for the Mentally Retarded in Erie County," the agency originally provided only referral services. However, the community needs changed in the mid-1970s and as a result of the deinstitutionalization movement, developmental centers across New York State returned more people with disabilities to the community. The agency responded to this situation by increasing service provision.

Today, PEOPLE, Inc. provides a broad range of services in the western New York region to over two thousand people with developmental disabilities and their families annually including: community services, developmental treatment centers, family support services, guardianship, in-home health services, multiple levels of residential services, respite services, senior services, social services, vacation services and vocational programs.

Project Description

PEOPLE, Inc.'s Adult Day Care Program (ADCP) opened in April 1989. It was developed because of the failure of existing programs to meet the needs of people with certain developmental disabilities. Many of the seniors with developmental disabilities were in day treatment settings where the rigorous and intensive requirements of such programs placed taxing demands on the elderly persons' physical and emotional reserves.

The Adult Day Care Program consists of two separate components which provide semiretirement options designed to meet different needs in two detached settings. One component integrates seniors into an existing social adult day care program in the community.

This part offers a semi-retirement option to seniors with developmental disabilities whose functional level is similar to the other seniors at the center. Through integration into an existing community-based center, these participants not only benefit from a quieter, slower paced atmosphere, but are also provided with the opportunity for true integration and a wide

range of choices for activities and social interaction. There are currently three individuals participating in this integrated component.

The other component of the program is a self-contained senior center housed in an agency building which serves twenty seniors. This program model was developed to give a semi-retirement option to seniors whose functional level is such that existing integrated centers would not be beneficial for them. It also allows individuals whose medical needs may preclude them from attending other programs to attend a day program.

The acceptance criteria for both components are similar: all participants must be 50 years of age or older; they must exhibit physical, psycho-social or cognitive changes related to aging; they must be limited in alertness, attentiveness and ability to tolerate large group social activities.

The agency-based program serves twenty individuals on site at the Buffalo Airport Center. Additionally, three other individuals have been successfully integrated into an existing community-based social adult day care program run by Catholic Charities of Buffalo. Program hours are Monday through Friday from 9:00 a.m. to 1:00 p.m. Staffing consists of a program director, program manager, habilitation specialist, program specialist and a parttime licensed practical nurse. PEOPLE, Inc. also assists in funding an aide position at the Catholic Charities site and assists with providing services -- including transportation -- to our seniors who attend this program.

Eight of our current participants are female and fifteen are male. The age range of our seniors is 52 to 79 years. Fourteen individuals reside in either Buffalo or Lackawanna. The remaining nine participants reside in other suburban areas of Erie county. One individual resides in a family care home, eighteen reside in certified residences (that is, either community residences or intermediate care facilities) and three live with family members.

Potential candidates for PEOPLE, Inc.'s



Adult Day Care Program are screened through the agency's central admissions department. A referral packet must include the following: an application for services, psychological evaluation, social summary, physical examination report, documentation of disability and a statement of the clients' rights and responsibilities. Referrals have come from a variety of sources including sheltered workshops, developmental treatment centers and the community.

Obstacles to providing services have included our inability to provide programming for individuals who require intensive behavioral intervention as well as those individuals who have extensive medical needs. We have been pleased to discover that individuals whose behavioral deficits have formerly been addressed in a more restrictive program, no longer required this type of program when a more flexible, individualized service is offered.

Some problems we initially encountered included our inability to fill the program to capacity. Initially, traditional day programs seemed reluctant to make referrals. This problem was addressed by in-service to staff from traditional day program models on the availability of a retirement option program, holding an open house, conducting tours for potential candidates and networking with other human service agencies to inform them of this new program.

Another barrier was the reluctance of some residential programs to refer their seniors to our program. Their hesitancy was based on the belief that our program goals would not meet regulations and guidelines. This necessary problem was especially true for ICF-MR programs. Also, a shortened program day and the ability to attend part-time created a need to staff homes during times that previously needed no staff. Again, the key to accessing this source for program participants included interagency networking and education.

Staff of the ADCP also had to do some revamping of traditional program activities and brainstorming regarding the concept of retirement for elderly people with developmental

disabilities. We achieved this goal by visiting senior centers in our community and adapting the activities to the functional levels of the participants in our program. Program participants are involved in a wide variety of activities based on their level of interest. Monthly activity calendars are prepared in advance with input from each participant. These activities include self-care, reality orientation, sensory oriented activities, exercise, group games, arts/crafts, cooking, music therapy and relaxation groups. Participation in these activities is optional with alternative activities offered.

Lessons Learned

Developing a program takes considerable administrative time which should be accounted for in the budget.

The original budget for the ADCP did not allow for many overhead costs. Although the costs of this program are great, they are still more cost-effective than day treatment and the value of such a program really cannot carry a price tag.

Our current annual budget for the Adult Day Care Program is \$107,429. Based on a maximum of 249 program days, the per diem cost per participant is \$18.76. This cost also includes transportation for 16 individuals. Unfortunately, the actual costs of the program are much greater than what is allocated, and therefore a deficit is created each year.

State policies regarding day programming for individuals residing in certified state-run settings should be considered so that more innovative program models can be developed.

We have learned many lessons from carrying out this project which included the need for non-traditional programs for seniors with developmental disabilities; preparing seniors with developmental disabilities for retirement to ensure successful transition; on-going research and staff; training for additional integrated settings and funds to expand existing programs through integration as well as

recognizing the need for non-integrated programs.

Parting Comments

If we were to undertake this project again, we would:

- Establish more rigid admissions/discharge criteria because the staff/senior ratio is not conducive to providing intensive services and yet referrals for individuals requiring intensive programming continue.
- Request funding for at least three full-time employees to ensure the quality of program

• Request adequate funding for transportation.

Our recommendation is to be innovative and adventuresome and not to try "reinvent the wheel" when it comes to service delivery. You may come up against some individuals who believe that seniors with developmental disabilities cannot benefit from this type of program. However, the ADCP has proven that participants can function optimally in an environment which offers options on a regular basis.

Remember, to listen to program participants. Our seniors have given us insight into our own history and have been important in the daily planning of activities and endeavors.

Rose Valley Senior Citizen's Center

Alvah Canfield¹

Case Abstract: This case study describes a senior center program located in rural southern New York. The program -- modelled upon a senior activities center -- provides a day program to a number of seniors with developmental disabilities as well as other seniors with similar functional skills. The program is part of the county's aging network with members involved in a range of activities outside of the center as well as inside the center. The program provides a model for a senior center/social model adult day care program.

Introduction

The Rose Valley Senior Citizen's Center is nestled in a small village in New York State's Catskill Mountains. The village of Monticello serves as the hub of activities for Sullivan County's primary provider of services to adults with developmental disabilities. The parent agency, Community Resource Center of Sullivan County operates a range of programs (e.g., day treatment, residential, sheltered workshops supportive work, clinic, ICF-MR), and has a contract with the area agency on aging to provide hot meals for the county's congregate meal sites.

Sullivan County is a rural area in the southeastern part of New York State with a population of approximately 65,000 people. It has no cities and its largest population center is Monticello which has 7,500 people.

Although there is a high percentage of senior citizens in the population, many tend to spend winters in warmer climates and for those who are year long residents, they are scattered throughout the county. Given the absence of population centers and no public transportation, there exists a rather underdeveloped network of aging services.



Correspondence should be addressed to Alvah Canfield, Ph.D., Director, Rose Valley Senior Citizen's Center, 45 Plaza Drive, Monticello, NY 12701.

Project Description

Rose Valley Senior Citizen's Center takes its name from Rose Valley Road and is located in the only building built in Rose Valley Industrial Park. The designation "Senior Citizen's Center" was selected to identify the Program with generic senior program and indeed, Rose Valley became the standard upon which other state programs are based.

Rose Valley Senior Citizens Center

The building, new and the partly occupied by the Center, is barrier free and is very much a multipurpose senior center.

The 7,500 square feet are divided into a cloak room; a lounge area with rocking chairs. couches, easy chairs; the great hall, a large area for common activities, community meetings and performances; a small service kitchen, though daily meals are not prepared; a sewing room; a small senior lunch room for special events; a nursing-therapy room with a bed, privacy screens, an attached bathroom and shower area and clothes washer and dryer; a viewing room with video equipment, accessible lavatories; a craft room with work table and deep sinks; a recreation room with ping pong table, shuffle board and other various games of chance; a conference room for staff meeting, counseling and special gatherings; an office with copy machine, computer, and other office equipment; and various office spaces for staff.

There are rugs in several areas and half of the building has picture windows with deep seated windows sills, each with potted house plants and greenery. There is an outside area with a gazebo, benches, gardens and container gardens.

The staff were hired with several things in mind. In general, the idea of a specific role was diminished in favor of a more universal, multifunctional employee. The interview process focuses on interests, avocations, hobbies, skills, talents, things that people enjoy doing alone and doing with other people. Such things as sewing,

gardening, needlework, woodcraft, community activities, game playing, cooking, reading, listening to music and artwork are looked for when recruiting both staff and volunteers. Orientation and training concentrates on the role of staff as supportive people who encourage independence, who look at themselves as teachers, and who understand the concept of the dignity of risk. The view is stressed that senior years are a time to grow, develop and learn things that were not done in earlier years. The practical aspects of multi-functional staff is that a wide selection of activities can be offered with a minimal number of people.

Within the present budget, there are 12 paid staff. There is a director, an administrative assistant and two managers: one for program planning and one for senior services. Other staff are defined as aging specialist. Of the 12 paid staff, one works 2 days per week, one works 3 days and one works 4 days per week. The others work 5 days per week. Volunteers from such programs as Senior Companions, Green Thumb, Retired Senior Volunteer Program (RSVP), religious groups, field placement college students and rehabilitation programs are regarded as non-paid staff and are eagerly sought.

A word must be said about management. As with other staff, management it is multifunctional. From the director on down, all have a case load and all are expected to participate in Center functions and to provide activities for seniors. The point is an important philosophic one. Everyone who works at the Center must have hands-on experience, no matter how limited, so that all share a common experience and have a personal involvement in providing services to seniors. The employment history at the Center indicate extremely low turnover rate with little difficulty in recruitment.

Most of the seniors at the Center are older adults with mental retardation or other developmental disabilities. Many of the Center's seniors have retired from sheltered workshops, others have retired from day habilitation programs. Several have come from skilled nursing facilities, several from intermediate care facili-

ties, several others from mental health programs and several from their families. At any given time, one can find sisters, daughters or wives bringing their family member to the Center. Some come because they have had strokes, encephalitis or have Alzheimer's disease.

Although enrollment varies, the Center serves 127 individuals with a daily average attendance 70. About 55 of the 127 people are full-time participants, attending five days per week.

As a basis for its program, Rose Valley staff constructed a taxonomy of needs. We felt that much of what we did should be based upon typical developmental tasks of aging — illustrated in the accompanying box. These definitions of the developmental tasks of aging were considered as valid for most individuals who are in the process of retiring. There are other tasks but these will suffice. The Center's philosophy states that to one degree or another all people share in these tasks. Thus, the sense that all elders are united by this concept of developmental tasks and that Rose Valley can provide an environment to work on those tasks.

Key features of the Center's philosophy include:

- The program is built on the premise that today must be experienced and enjoyed for itself, not as a preparation for tomorrow or a prelude to some future time, but for itself. The program emphasis is "on doing," on activities. The Center does its best to do away with self-limiting reasoning and devaluating the present time.
- The seniors choose how they spend their time at the Center. For many people this is the first time they have been asked to make decisions about their lives. Individual goal planning is not done. Of course, seniors are not abandoned to indecision but are encouraged and guided to assume responsibilities for themselves.
- Motivation is not postulated to come from programmed behavior modification techniques, but rather from the intrinsic value of

Developmental Tasks of Aging

- doing life reviews
- · providing services to others by volunteering
- adapting to retirement, changes in power, income, pressure, expectations, responsibilities, life rhythms
- changing roles and self-concept
- · coping with social and physical changes
- · learning leisure and recreation skills
- · accepting the need to rest and relax
- understanding "interiority" -- learning about self and values inherent in later lifecycle stages
- accepting death, losses and one's own mortality
- involving in social rites of passage -- senior ID cards, Medicare, Social Security, pensions, congregate meals, AARP
- growing and developing with each change in the life cycle

the activity and from the intrinsic value of participating in the experience of the day. This value is a deliberate application of the ancient principle of hedonism. Simply stated, seniors do things and engage in activities because they like them. It thus becomes incumbent upon our staff to provide a daily schedule which offers a wide selection of activities with high motivational interest, from which individuals can exercise choice.

Rose Valley is currently an unregulated program. In time, it may evolve into a social adult day service program and take its guidelines from regulations issued by the New York State Office for the Aging. But for now, it has license to develop new ways of relating to people and developing age-appro-



Casebook of Program Ideas in Aging and Developmental Disabilities

priate alternatives. Ultimately, the desired outcome is to bring seniors with handicaps into the mainstream of senior activities in New York State.

The Center's program is built around five major areas: leisure time, recreation, personal needs, social activities, and community activities. For the most part, the interest areas are self-explanatory. All the elements of the program are tied together through the daily schedule which is a detailed plan for an entire week including activities, time frames and staffing.

- The organized part of the day begins around 9:00 a.m. when the last bus unloads its passengers. All seniors meet in the great hall for the following announcements for the day (e.g., guests, field trips, medical appointments, etc.), several minutes of senior exercises, the sign of the day (sign language), special events (birthdays, historic events, current affairs), humor for the day and poem for the day, etc.
- Then follows a morning march through the building and outside, if weather permits. The march has a purpose beyond the benefit of physical exercise. The route of the march takes people by all of the exits and on each day a different exit is highlighted. In this way the consciousness of seniors is alerted to alternative emergency exits.
- On the return from the march, seniors select one of five small groups that meet to do interactive socializing, to learn new things or simply to talk about movies or TV, or what one did on vacation. The seniors then have their morning coffee or juice. Thereafter, the rest of the day begins. The community meeting takes somewhat over one hour. The daily schedule then calls for seniors to do individual projects, take field trips, listen to old radio programs or music, meet with guests, or play games. Some seniors may just choose to sit and talk.
- Lunch begins at 11:30 a.m. and ends at 12:30 p.m. Then, the feature film of the day begins in the viewing room, the second field trip goes off and much of the afternoon follows a similar pattern to that of the morning with projects, guests and the like.
- The day ends when the buses begin to transport

people home shortly after 2:30 p.m., with the last bus departing around 4:00 p.m.

The daily program accommodates the certainties of the day: the transportation schedule, eating schedules, medication schedules, toileting needs and the desire to have consistency and routine. However, the challenge is to vary the offerings without doing harm to the certainties. Developing a schedule around given routines helps to break the daily block of time into workable frames, planning becomes manageable and variety can be built into each day's schedule.

Several segments of the Center's daily schedule involve community contact. There is no history in Sullivan County of a systematic use of community resources for handicapped seniors. Much of what is done now is done in the spirit of exploration to see what the county has to offer. Rose Valley has developed the view that it belongs in the community, wherever possible, and that the community belongs in Rose Valley, whenever possible. It is in this sense that community-based programming is regarded as a two-way street.

Not only do Rose Valley's members visit all the tourist sites, shopping centers, craft fairs, county fairs and cultural attractions in the area but they have an active association with the Office for Aging (OFA) which involves visits to senior nutrition sites, to senior citizen clubs and other functions sponsored by the OFA. In addition, the OFA issues to Center members, senior citizen cards, similarly eligible Rose Valley seniors are registered as RSVP volunteers for the services they render.

The Center has developed an active volunteer program. Rose Valley's members deliver Meals on Wheels for the OFA (Center staff are drivers), they do Friendly Visiting at the county nursing home and at the our local hospital's skilled nursing unit, they participate in community gardening programs, serve in the Salvation Army Food Program for the homeless, and our Senior Singers visit a variety of programs representing Rose Valley. These are some examples of how seniors can become part of the community,

The second phase of community involvement begins with the technique of the open house. The Center has identified organizations and groups in the community with whom it wants to establish contact. Individual organizations are then invited to an open house which is scheduled on a monthly basis. The event usually entails a tour of the facility, a short presentation of the Center philosophy, a luncheon of homemade soup and sandwiches, and an exchange of names and telephone number for further contact. The invitation list includes: public health department, cooperative extension, OFA, community college, Animal League, community hospital, business owners, other rehabilitation and senior programs and any group with whom positive relations are desired.

These initiatives have brought about many program innovations, such as pet therapy sponsored by the Animal League; health programs sponsored by American Heart Association and the Cooperative Extension; and religious instructions and celebration by churches and synagogues. Other guest programs have included those provided by veterans organizations, law enforcement officers, postmasters, and the ambulance corps.

For many of these special events, the opportunity is present to invite other seniors from the county to attend. In this way, Rose Valley provides a public service to the community by offering programs of interest and thereby fostering integration within the Center itself.

Lessons Learned

Beginning a new program in an area where there had not been one before presents an opportunity to build from the ground on up with every decision representing a new learning experience. Within this context, it would be impossible to recount lessons learned without being highly selective. Thus, what has been learned from the experience will be, of necessity, incomplete and non-sequential.

Have a clear philosophy or intent to your program.

The philosophy of the program is critical.

Seniors, staff, the community and collateral agencies all need to have a clear understanding of the goals and purposes of the senior program. A philosophy is significant in recruiting new participants, in hiring staff, in developing orientation and training programs. In short it underscores so much of what the program stands for. It takes time to put the orthodox views aside and look with fresh eyes on what is the reality of the program for the elderly. If the needs of seniors are really to be met then at some point these needs must be defined. The first goal must be to evolve a philosophy and project a vision.

Not all staff or members of your community share your attitudes or values.

Attitudinal problems come in every form and at every end of the value scale. Views such as: handicapped seniors are volatile and dangerous; they are cute and like children who must have everything done for them are ever present. Bias resides in the seniors themselves, in staff, in the community, in other organizations. It is difficult to understand how often people will not see what is immediately before them but revert, so readily, to the idols of the cave. For Rose Valley, the accepted wisdom about what seniors can and can not do became a major barrier to the development of the program. It conditioned the selection of seniors for the program, it was an issue for selecting and training staff, it was a concern when designing the Center's programs and working with collateral. It was disappointing to discover how little confidence habilitation and rehabilitation workers had in their ability to develop the potential of the people they served. It was as if there was ideology that precluded change and seemed to provide a justification for the services performed -- whether the services were needed or

A brief example of the effects of attitude on the program is needed: The accepted wisdom was that seniors would not leave sheltered employment because they would not go to a program that did not pay them. This sentiment was present at pre-retirement interviews with seniors and with employers and counselors. There was an obvious bias against retirement. Staff regarded it as the first stages of decline: decline in productivity, loss of power, Casebook of Program Ideas in Aging and Developmental Disabilities

loss of income, loss of friends; it was seen as the slow move to isolation and to the grave. These were strongly held feelings and seniors and staff reinforced each other.

Clearly, these sentiments represented more the projections of the staff than the introspection of the seniors. The Center can not control attitudes but it can plan for and set expectations of behavior. The hope is that in the long run, attitudes will be influenced.

Parting Comments

Many of the barriers Rose Valley faced were met and confronted by a commitment to the philosophy and the vision of the program. It will be noted that most of the concerns of the pre-retirement interviews raised by seniors and by staff are items contained in Rose Valley's paradigm of developmental tasks of aging. These are real issues that need to be demystified and treated as normal life-course concerns.

The approach of the program is to address issues with patience and to provide learning experiences for all sectors of the field. The view is to start small, with enthusiasm and with an experimental perspective. The Center has a gentle, but pervasive motif: "do not be self-limiting, let whatever limitations there are be imposed by the objective conditions of the world not by inner thoughts or the absence of creative planning." For Rose Valley this motif guides us in working with individuals, with collaterals, with the community, and with all of the program.

These are exciting times for seniors who for most of their lives have been excluded from the mainstream of society. Public relations, networking and -- to use a contemporary term -- marketing must become part of the day to day and long-term planning. These new aging programs are not only cost-effective but have the ability to assist individuals in participating in their own personal growth and development that is congruent with their life stage. The benefits are self-evident.

DASH, Inc.'s Other Place

Vicky L. Dickinson¹

Case Abstract: This case study describes a social model adult day care program in Redlands, California that worked toward integrating seniors with developmental disabilities into its program structure. From the perspective of an aging network agency, the operators noted some of the organizational and administrative barriers they encountered in getting their program accepted as a developmental disabilities program alternative within their community. These included a lack of referrals and funding, some of which were related to an unfavorable economic climate.

Introduction

Developing Aging Solutions with Heart, Inc. (DASH), is a not-for-profit organization which was established in 1979. Its purpose is to develop and implement programs and

services for the elderly with dementing illnesses, physical limitations and developmental disabilities. Additionally, the agency's mission is to support and educate families with regard to caregiving responsibilities.



Correspondence should be addressed to Vicky L. Dickinson, Director of Program Development/Education/Research, Developing Aging Solutions with Heart (DASH), Inc., 306 West Colton Avenue, Redlands, CA 92374.

One of the services DASH, Inc. provides is "The Other Place" Alzheimer's Daycare Resource Center which began in 1985. "The Other Place," located in a neighborhood home in Redlands, California, is a social treatment program that addresses the physical, social, emotional, cognitive and spiritual needs of the participants. The objectives are not only to meet the participants' needs but also the family caregivers and the community needs. Adult day care provides a viable and economical alternative to "fill the gap" on the continuum of long-term care which exists between institutional and home living.

Project Description

San Bernadino County is one of the nation's fastest growing area and includes rural, urban and desert areas located in and around the county seat. The county is divided into the desert region and East and West Valleys, which include seventeen cities as well as unincorporated areas. Some 53,000, or 6%, of the county's 893,000 residents are age 65 and older.

"The Other Place" is situated in a house in an East Valley neighborhood that is predominantly Afro-American and Hispanic in make-up. The home meets the requirements of an historical site because of its bungalow style architecture of the 1950s. The house was remodeled to bring it up to fire, sarety, health and accessibility codes. The home's interior consists of two accessible bathrooms, a living room, parlor, kitchen, recreation rooms and two offices.

Our program is licensed by the California Department of Public Social Services' Community Care Licensing Division, which is also responsible for monitoring daycare centers for adults and children, board and care homes and foster care homes, and administering the licensing laws and regulations for community-based programs. We are licensed to serve on a daily basis twenty individuals with functional impairments age

45 and older. DASH specifically asked to be licensed to serve older individuals with developmental disabilities so that these individuals could have other opportunities to socialize with peers outside of their sheltered workshop, activity center, nursing facility, or board and care environments.

Participants are referred to our daycare program by family, friends, social workers, physicians, and clergy from board and care and nursing homes, the regional center for developmental disabilities, adult protective services, and hospitals. Potential participants must have either a developmental disability, functional impairment, or a physical limitation that without daycare would make them vulnerable or at risk of premature institutional admission.

Our participants fall into two or three of the categories mentioned above. Additionally, our admission requirements state that the participants may not pose a threat to themselves, others, or property. Special care needs such as toileting, eating, ambulating and health monitoring can be met by the staff and volunteers. Each individual is assessed with respect to his/her functional level, strengths and stressors, ability to tolerate the group setting, and the anticipated benefits that he/she may receive through his/her participation in the program. Sponsorship funds, when available, are used to assist individuals who have the greatest social or financial need. The per diem is **\$**30.00.

When the program opened in 1985, DASH applied to the Inland Regional Center, our developmental disabilities administrative center, for consideration to be authorized as a day care program serving adults with developmental disabilities. At the time there were no adult day care centers in the county. This authorization would allow referrals to be made to our program. In addition, the Regional Center would assign a social worker to the day care program responsible for assisting with the individual habilitation plans on a quarterly basis joint-



ly with DASH staff. Thus, the senior would have day care services and transportation paid for by the Regional Center. "The Other Place," after a year, received authorization to serve a total of five individuals with developmental disabilities. This authorization meant that we could receive funds for serving five persons.

In six years of operation, "The Other Place" has served over 200 individuals with dementia and/or physical limitations but only a limited number of individuals with developmental disabilities. "The Other Place" received a number of referrals from families of individuals with developmental disabilities. One of these individuals had never been seen by the Regional Center for services; another had been a long standing participant whose mother had been a strong advocate for the rights of individuals with developmental disabilities. A number of adults with cerebral palsy were also referred from a board and care home. They remained with us for a number of months. but eventually left because we couldn't obtain funding for their participation.

In retrospect, having had only a few individuals with developmental disabilities referred was most likely due to a number of factors. One was a lack of understanding among potential referral sources of how well a senior with a developmental disability could do in a program that traditionally only served seniors with age-associated limitations. Another was a shortage of funds to cover the per diem due to state budget cuts.

The barriers which exist between DASH and the Regional Center have yet to be fully overcome. Progress was made when the Regional Center recognized the need and benefits of adult day care. Once "The Other Place" became authorized to receive participants, the Regional Center did assist with the development of other new centers in our area specifically to serve this population.

Notwithstanding the problems we experienced with obtaining referrals, our experience with integration in adult daycare has been positive. The staff played an essential role in helping the seniors become more tolerant of each other and kinder during their interactions. Seniors who initially had been less tolerant were generally having difficulty accepting their own limitations, were more highly functioning, and, as a result, tended to look down on less functional individuals regardless of the nature of the disability.

These difficulties were dealt with during small group discussions where the more functional seniors were given the opportunity to talk about their feelings of loss associated with the aging and disease process. All seniors were expected to participate in activities that involve the group. Staff assisted the seniors with this process by validating the individual's feelings and at the same time reminding him/her of his/her innate quality to be the kind, benign person he/she knows he/she is and is capable of demonstrating.

Lessons Learned

Project developers must anticipate problems before they arise.

Problems, such as not knowing enough about the population to be served, the needs of the community, and the lack of key players who agree that the need for daycare exists, may limit funding possibilities. Likewise, learning more about licensing requirements and the politics of the community may assist a program developer in his/her mission.

Learn about foundations and/or service clubs that might assist in programming.

The United Way is helpful with issues of fundraising, recruiting board members and volunteers. The area offices on aging will also lead you to other appropriate resources. A pro bono lawyer who



can answer your questions about the legal requirements for establishing and maintaining a not-for-profit organization will save much money.

Daycare directors should become involved with helping to initiate and develop policy at all levels of government.

This challenge can be addressed by becoming an active member of community coalitions, state and national associations and writing letters to legislators.

Parting Comments

DASH, Inc. has achieved all of its original goals and objectives and continues to maintain them while creating new goals. If we were to undertake the project again, we would have avoided some of the start-up problems we encountered. However, at the time of the program's implementation, daycare was not viewed as a viable long-term care alternative nor were funds available to hire staff. What we have learned should be of benefit to other program developers. The creation of new ideas and services bring about the pioneering conditions.

These must be undertaken for an alternative to institutionalization to become a part of our continuum of long-term care.

There is merit in providing integrated programs and services for elderly persons with limitations and is a social responsibility for community-based organizations. Social action is vital to community, family, and program participant growth. However, as programs respond to these needs they also must remember that they have to be accountable to the consumer and his/her family.

Area agencies on aging, state departments on aging, and state departments of developmental disabilities play an important role in leading the way to collaborative relationships that can help at the local level. These agencies can set the tone for how community programs may create integrated programs for the elderly with limitations who are at-risk of premature institutional admission. Policy development and a strong funding base will help to proliferate daycare centers and various eldercare programs for family caregivers.



av Health Model Programs

A variant on the adult day service model is the adult day health program. These programs are essentially similar to the social model programs with the exception that funding generally comes from Medicaid or other health care payments and admission is by physician's referral. Because of this, some services also involve specialized therapies; other services tend to be more medical, such as health monitoring, medication administration and review, as well as nursing care. Other activity services are similar to social model adult care services. These programs exist in many communities, although in not as great a number as the social model programs. Because of the nature of the services, most of the programs serve seniors who are frail or recovering from illness or surgery, with more severe levels of impairment or disability, and some older persons with lifelong or developmental disabilities.

A number of the examples of community programs that we came across were of this type. Many were interested in expanding their clientele to include seniors with developmental disabilities. The following section illustrates two efforts by adult day health providers to accommodate seniors with developmental disabilities.

The lessons learned? As they move to serve persons with developmental disabilities, health providers find that their patients enter a system which has differing requirements. Program activities need to be designed to accommodate a variety of impairment levels and interests. Such program efforts are doable, but care must be taken to expose staff, often who have worked solely with persons whose primary need is health care, to habilitative technologies and knowledge about developmental disabilities. Also, case mix issues need to be worked out as in some instances, persons with a developmental disabilities may be as impaired as others using the program, whereby in others, the admission may be a matter of convenience. Although these program may at times be most costly than other types of formal day programs, they provide an opportunity for elderly persons with significant functional impairments to receive a range of services and activities in a comfortable day program environment under the supervision of medical or health personnel.



Community Family Day Health Program

Nancy Sherman¹

Case Abstract: This case study describes the experiences of a health model, adult day care project in Everett, Massachusetts which serves the elderly and adults with various disabilities. Recreational and social activities, medical monitoring personal care and respite are offered. It was found that flexibility in programming for each individual is important and modifications in program activities or days scheduled may be required. Periodic inservice training including behavior modification techniques and frequent open dialogue between staff is recommended.

Introduction

Adult day health (sometimes referred to as medical adult day care) was created as a means of providing adults with disabilities with the opportunities for socialization, medical monitoring and personal care assistance. By offering these services, family caregivers have received respite, and participants have been able to remain in their own homes and communities for as long as possible.

The Community Family, Inc. is a non-profit, community-based, health care agency which began in 1978. Its purpose is to serve elderly adults that those with adults with chronic disabilities who have long-term care needs. The primary purpose of the organization has been to prevent unnecessary hospitalization or nursing home placement, and to provide support to families and other caregivers with assistance to help them cope with the demands of caregiving.

The Community Family, Inc. operates three programs north of Boston, Massachusetts. In addition to on-site services, the agency also offers educational services, caregiver support groups, and in-home consultation and education. The educational and support groups offer caregivers the opportunity to gain additional information about such topics as aging, dementia, legal and financial concerns, available resources, and behavior management; and the chance to interact with professionals and peers.

This case study focuses on the Community Family's Everett program. Everett, a city of some 35,000 persons, is predominately blue collar and comprised largely of persons of Irish-

and Italian-Catholic backgrounds. About 17% of its population is made up of persons age 65 and older.

The Community Family believes that many of the needs of the aging population with mental retardation are similar to, if not the same as, those of the general aging population we have traditionally served. Professionals accustomed to working within the systems designed for persons with mental retardation are often not aware of the many service options outside that system, or aware that these other services would consider integrating people with mental retardation into their programs. Thus, the Community Family has developed and maintained a goal of reaching out to service providers within the mental retardation field to acquaint them with adult day health services, to encourage their use of our programs, and to successfully integrate the needs of the population with mental retardation into the overall program.

Project Description

The Everett program is situated at a store-front location in the heart of the city. The program uses a multi-disciplinary team approach to ensure coordinated, quality care. It is licensed to serve 36 adults per day and has a staff-to-senior ratio of 6-to-1. The total caseload is about 60 adults. Participants come to the program 2-to-6 days per week, the frequency depends upon on their interest, payment resources, and the program's ability to meet their needs. The program operates Monday through Saturday from 8:30 a.m. to 3:00 p.m. and includes nursing care, social services and recreation therapy.



Correspondence should be addressed to Marilyn Mulligan, Executive Director, The Community Family, Inc., 138 School Street, Everett, MA 02149.

The executive and clinical directors of the Community Family are principally responsible for marketing the programs, although the program's social worker also plays a significant role in this endeavor. Our marketing involves public speaking engagements, obtaining media coverage at regular intervals (often using a special event held at the program as a story focus), and encouraging ongoing referrals from regular referral sources. In addition, a thank you and initial progress note is sent to the referral source approximately two weeks after a senior begins the program.

The program social worker is also responsible for writing a brief description of all new service participants, including their interests and any special information, and posting this information for all program staff to read the day a new participant begins the program. At regular staff meetings, which are facilitated by the program social worker, all staff are encouraged to share their feelings and observations of the participants who have visited the program for an intake and those individuals who are already participating. Although the program's social worker is responsible for participating in, or initiating if necessary, any meetings with other community resources, the clinical director may also take responsibility for this task if his/her authority is indicated. The clinical director is responsible for the program's overall functioning.

The Community Family's programs are licensed by the Massachusetts Department of Public Welfare which also reimburses much of the services (through Medicaid). Some service recipients are able to use Executive Office of Elder Affairs respite funds through local home care corporations, or funds from the Massachusetts Commission for the Blind, while others pay for the program privately. Program referrals come from a variety of sources, including home care case managers, discharge planning departments of hospitals, local councils on aging, and case managers from the state's mental retardation agency.

Transportation to the program is arranged by the Community Family's van, private transportation services with whom the agency has contracts, taxicabs, and families. Although anyone over the age of 18 is eligible for services from the Community Family, most participants range in age from 40 to 90 with the average age being 78.

Individuals who are considered appropriate candidates include: chronically ill or disabled adults who are limited in their mobility or selfcare abilities and who require routine supervision or assistance with care; individuals whose families require some respite in order to maintain them at home: individuals whose families may wish to maintain their family member at home, but find full day supervision difficult due to other demands on their time (e.g., employment, children); individuals who receive or require large amounts of home-based care (e.g., the use of home health aides, homemakers, etc.) and for whom it might be more cost-effective and beneficial to receive care in a group setting of care; individuals who need a broader range of therapeutic services than might be available in a senior center, social adult day care or another type of program; and individuals discharged from a hospital or nursing homes who require a supervised program or adult day health services which will assist them in the transition back to independent living.

Although there is variation in the program day and in the activities offered, the staff have found that participants do not like too much change from their daily routine and favorite activities. The following schedule describes a typical day:

- 8:30 9:15: Arrival. During this time, participants are greeted by staff and seated at a table with other members with whom they can visit. The staff mingle among the tables, interacting with and encouraging conversation. Shortly after 9:00, a ten minute exercise class takes place. Those seniors who are able, are encouraged to stand and move, while others participate from their seats.
- 9:15 10:00: A light breakfast is served.
- 10:00 11:00: Those seniors who are able



Ms. Pauline M.

Ms. Pauline M., is a 74 year old woman with mild to moderate mental retardation who has been in the program for two years. She lived in a state school from age 17 until age 66. She then went to live in a community residence and attended a day activities program until the staff felt that they could not continue to give her the attention she needed.

Ms. M. works well in quiet, small settings with direction from staff. She prefers one-to-one attention with few distractions and she responds very well to the techniques commonly used with all service recipients by the Community Family staff. She was originally admitted on a trial basis which proved successful, so she was enrolled in the program for two days per week, where she has continued.

During the program day, Ms. M. participates in morning and afternoon exercise to music. Although she is reluctant to engage in much actual movement, she does clap and sing and is very enthusiastic. Typically, she spends her days playing a staff-directed game with three-to-five other participants, enjoys creating something in arts and crafts, or take part in the program guest entertainment or the bi-monthly mass. Without a special event, Ms. M. prefers the smaller, quieter group of adults (five-to-ten people) who spend the afternoon resting, watching a movie, and/or talking.

Once per month, Ms. M. meets briefly with the program nurse who checks her medical condition (weight, blood pressure, pulse, etc.) and brings up any concerns she has about her health.

and inverested, play "Bingo," while another group participates in an "arts and crafts" activity or plays another game. (Crafts include "paint by numbers," knitting or crocheting and making holiday decorations. Other games include a version of "Trivial Pursuit," a

- horse racing game, cards, and "Scruples.")
- 11:00 11:45: Rest period and/or participation in current events discussion (often initiated by reading the paper).
- 11:45 12:45: Lunch.
- 12:45 2:45: Community outings, entertainment (sing-a-long, school children performing, etc.), games, small group discussions, poetry reading and visits from religious leaders such as priests.
- 2:45 3:15: Departure.

It should be noted that all of these activities have a senior-to-staff ratio of 6:1. Throughout the day, a registered nurse is not only available to participants who may have a question or problems, but also to perform routine medical monitoring, such as weight and blood pressure checks.

Typically, seniors enter the program following an intake procedure. This procedure usually involves the individual visiting the site for about one hour, and joining in a program activity. During this visit, the program nurse, social worker and activity director have an opportunity to talk with and observe the potential service recipient and gather additional information from prior records and/or conversations with family and/or professionals who are involved with the person.

Following the visit, these three staff, (considered the professional team) meet to discuss their observations and recommendations regarding the individual's appropriateness for the program. Individuals who have a diagnosis of mental retardation and who meet some of the above criteria are incorporated into the Community Family's programs.

Regardless of intellectual abilities, as people age many of their needs, as defined by the program's eligibility criteria, are relatively the same. In addition, many of the program participants have been found to be tolerant and accepting of differences, and especially observant

and helpful with those individuals with mental retardation who may require more assistance than the average person in the program.

It is difficult to generalize about the reactions of participants to someone with mental retardation as, regardless of diagnoses, there is always the occasional personality conflict stemming from any of a variety of factors. In addition, many participants in the program appear "different" due to a number of problems such as stroke, multiple sclerosis and crippling arthritis so that initial impressions tend to be accepting and compassionate.

During the program's twelve years, there have been a number of individuals with a diagnosis of mental retardation. For example, two of the most recent service recipients, who are representative of others we have served, are described in the accompanying vignettes.

Lessons Learned

This type of program is very affordable.

The program is reimbursed through a variety of resources. Our program is rate-driven and regulated by the Commonwealth of Massachusetts' Department of Public Welfare (which administers the stated's Medicaid plan). The current daily rate is \$30.65. This rate does not fully cover the administrative costs associated with the program, and therefore, the Community Family has diversified its services (by operating two other programs) in order to recover the administrative costs. In addition, private pay rates are slightly higher.

It should be noted that each of the Community Family programs is free standing. In order to absorb administrative costs, other adult day health programs are often associated with a larger entity, such as a nursing home or hospital. Naturally, because the Community Family is a not-for-profit agency, the goal with respect to cost/benefit concerns, is solely to "break even."

Because the Community Family is licensed and reimbursed by the state's public welfare depart-

Mr. Richard P.

Mr. Richard P. is a 62 year old man with mental retardation who is legally blind. He lived in a community residence and attended a sheltered workshop for many years before he moved to the home of his younger sister and brother-in-law. This move was precipitated by medical complications following a stroke in 1982. After the stroke, Mr. P. was confined to a wheelchair. He was incontinent and depressed.

Mr. P.'s sister requested that he participate in the program because she felt that she needed some relief from caregiving responsibilities and that he could benefit from the socialization and stimulation. We believed that his primary needs fit the eligibility criteria and that admission seemed appropriate. Most of Mr. P.'s needs and behavior resembled those of many other Community Family service recipients (i.e., he was non-ambulatory, legally blind, he had communication difficulties and he was incontinent) so that he was comfortably and readily accepted by other service recipients.

Although some interventions were individualized as needed, Mr. P. responded positively to many of the methods used with all service recipients (such as personal care assistance, participation in activities, physical affection, personal attention). Mr. P. was able to participate in the program until his medical condition deteriorated to the point that it was no longer possible to care for him adequately within the program. He was subsequently discharged and admitted to a nursing facility.

ment, we work closely with other adult day health programs and the Commonwealth's Executive Office of Elder Affairs (which acts in a lobbying role to advocate for adequate rates for providing quality services, as well as participating in the development of guidelines, policies and procedures which impact the service population).



Integrating people with mental retardation into the adult day health program is an ongoing endeavor. Staff associated with the program should continuously be learning and looking at ways in which to make this type of effort successful.

Due to the way the program continues to receive requests for information and referrals from service providers within the mental retardation system, the goal of educating the professionals within this system seems to be achieved. Nevertheless, the Community Family continues to seek ways in which to reach this population further. The Community Family also continues -- through team meetings -- to educate itself and remain open to ways in which to make the program beneficial for its participants with mental retardation which is another goal that the program has met.

☐ Integrating individuals with mental retardation into the program can occur rather naturally as the program is growing.

Review of a particular person's appropriateness for the program arose regardless of diagnoses. It was made clear by program management that people would at least be considered for the program regardless of whether or not the program could, as it was structured, meet the individual's needs. There has also been an ongoing message from management that staff must remain flexible and willing to make minor adaptations in order to accommodate individual needs, as long as the program as a whole is not jeopardized. This type of message and support from administrative personnel is essential, as is providing staff with the tools to accomplish this goal (i.e., education, information, resources, and supervision).

It goes without saying that, if a program administrator were thinking of expanding his/her program to include individuals with mental retardation, never having done so before, it would be of the imperative that discussions with staff be held. These discussions must focus on explaining goals, rationale, what will be required of staff and what will be provided for them to achieve this goal. Furthermore, the discussion should take place prior to implementing this plan.

We have been able to integrate all new seniors into the program in essentially the same manner.

All new participants are introduced by name and with some identifying information which will facilitate connections between participants (such as their place of residence or some other similarity they may have with another participant). Seniors with mental retardation are not segregated in any way. All seniors are invited to participate in whatever activity is going on at a particular time. Those individuals who may need assistance in becoming involved are helped by a staff member (individually or in a small group) or, if appropriate, by another participant. Although most of the seniors seem not to be affected by some fellow seniors' behaviors or limitations, on occasion, a senior may have some difficulty. During times such as these, staff will attempt to separate these participants when possible, seating them at opposite sides of a room or perhaps talking with the individuals who are complaining. These discussions do not focus on a diagnosis (i.e., "be patient with him, he's retarded"), but instead on differences (i.e., "I know it can be annoying for you, but please be patient with him, he takes a little longer to catch on.")

Having a strong, supportive Board of Directors which is informed of general programmatic directions and indicates its support for this effort is important.

Depending upon the type of organization, this understanding and support may also be useful if not crucial to gaining additional staff and/or community support. The Community Family enjoys a positive reputation as a provider of long-standing, quality adult day health services. There have never been any negative repercussions to including people with mental retardation in the program. This outcome may be due to the variety of individuals with various diagnoses, and also to the matter-of-fact and compassionate approach of the program staff to those individuals who visit the program (i.e., other professionals, family members and potential service recipients).

Parting Comments

Although specific modifications will vary with each program, the example of Ms. Pauline M. clearly demonstrates the value of "trial" days in assisting in the assessment process. In arranging intake/assessment visits, we found it helpful to consider visiting the potential service recipient in a setting that contributes to his/her comfort, such as his/her home or workshep. Although the program day is generally six hours, it may be possible to integrate and serve an individual who cannot tolerate more than a four hour day. It is also essential that regular communication be established and maintained with individuals' families and/or other service professionals.

Modifications in program activities or days scheduled may also be helpful. Some of these modifications include scheduling an individual on days when other participants are known to be more tolerant or helpful, or when activities planned for those days will be most interesting to or possible for the person with mental retardation; allowing the person to "sit out" a difficult activity; providing staff assistance or activity modifications to allow individuals to join in, such as large number Bingo cards or someone pointing out the numbers called.

The program social worker also checks with each participant to see how he/she is feeling about the program, if he/she has any problems or needs. There are also ongoing and frequent discussions with community-based staff (including participation in the yearly development of individual service plans) for those participants coming from the mental retardation system. These discussions have enabled the Community Family staff to remain aware and understanding of each individuals's needs, while ensuring that comprehensive, integrated services are being provided. It should be noted that the program social worker is primarily responsible for this linkage, although other staff have, upon occasion, been involved.

The Community Family is pleased to have welcomed its first service recipient with mental

retardation into the program many years ago. As stated previously, this goal is an ongoing effort, and consequently staff are always learning and considering new and different ways in which to make integration successful. We have learned that flexibility is the essential element to the success of this type of endeavor. In other words, if a program insists upon adhering too narrowly to defined admission and/or participation guidelines, it will be very difficult, if not impossible, to accommodate what may be minor differences displayed by a person with mental retardation. It may go without saying that it is not recommended that a program make so many adaptations that participants with mentally retardation end up being isolated, segregated or continually characterized as different; the goal is normalized integration.

Specific suggestions of possible modifications have been made. It should be repeated that, in addition to flexibility, another essential ingredient to comfortable integration is that program management must provide the motivation, support and resources necessary for successful integration. Although many individuals' needs are basically the same regardless of diagnosis, and the staff may need to be reminded of this fact alone, periodic in-service training for all staff regarding mental retardation is helpful. Included in this training should be an understanding of the uses of behavior modification.

In order to avoid any possible misunderstandings or tensions between day program staff and other personnel who may be involved with an individual with mental retardation, frequent and open dialogue is highly recommended. There are occasional differences in techniques or philosophies between the two systems, and it is important that discussion be generated which allows for explanations as well as resolutions.

Overall, the Community Family has found the Ategration of persons with mental retardation to be a successful and rewarding endeavor, with the benefits exceeding the minimal extra effort which may, upon occasion, be required.

Day at the Park

Diane Donaghue¹

Case Abstract: This case study describes the experiences of a Medicaid certified, daycare program in Rochester, New York. The agency serves a 50/50 participant mix of seniors with mental retardation and other seniors. The provider found that when serving persons with a developmental disability, special considerations need to be undertaken, including training of staff, considerations of case mix, and working with the residential provider.

Introduction

Day at the Park is a medical model, integrated daycare program located in a multi-level health care complex in Rochester, New York. Day at the Park is housed in a new building annexed to a nursing facility. The building is on one level and covers an area of approximately 4000 square feet. The facility is decorated in pastel pinks and blues, and presents a very "home-like" atmosphere. The building is almost completely surrounded by windows.

The program opened in April 1990 as part of the Park Ridge Hospital and Health System which offers acute care, long-term care, chemical dependency treatment, mental health and senior housing services. The program provides vital health care services such as nursing care, personal care, nutritional services, social work, recreational therapy, psychiatric consultation, medication administration, podiatry, and dental care.

A major goal of the program has been to integrate a large number of elderly individuals with developmental disabilities into a program for elderly individuals who do not have developmental disabilities.

This setting provides the elderly registrant who has a developmental disability the opportunity to "retire" from the strenuous day treatment or sheltered workshop program while continuing to receive health care and the opportunity to participate in a less rigorous recreational program.

Project Description

Day at the Park is open weekdays from 7:30 a.m. until 5:30 p.m.. The program is licensed by the New York State Department of Health and can serve up to 30 registrants per day. Approximately 50% of the registrants have a diagnosis of mental retardation or of a developmental disability. The remaining have such diagnoses as Alzheimer's disease or other dementias, diabetes, stroke or arthritis.

Because we are a Medicaid certified program, registrants are required to attend at least one day per week for at least three hours. Most registrants attend between the hours of 9:00 a.m. and 3:00 p.m. The per diem cost is \$87.00 which is covered by Medicaid for eligible participants.

The day care staff consists of the director, a registered nurse, a social worker, a recreation therapist, a recreation therapist aide, five program assistants who are also certified nursing assistants, a receptionist, a consulting dietician, and therapists.

Many of the registrants who attend the program could qualify for placement in a long-term care facility, however, caregivers and the provision of other support services allow them to remain in the community. The program is not designed for people who only require socialization or are otherwise stable or have behavior problems which do not respond to redirection or to a simple behavior management program.

Planning for integration occurred when administrators from the regional health systems agency, the Park Ridge Nursing Home and the



Correspondence should be addressed to Diane Donaghue, R.N., B.S.N., Director of Adult Day Care, Day at the Park, Park Ridge Health System, 1555 Long Pond Road, Rochester, NY 14626.

regional office of the state's developmental disabilities agency met. At the time, the developmental disabilities' agency staff was planning to open a community residence near Park Ridge. The purpose of the community residence was to allow the 10 residents to retire from day treatment programming. The opening was scheduled around the same time as the opening of the Day at the Park program. It was decided that the 10 residents of the Greenbriar Community Residence would attend Day at the Park for five days per week.

Several case reviews were held between the clinical staff of the state's developmental disabilities agency and the clinical staff of Park Ridge Nursing Home, who also happened to be on the Adult Day Care planning committee. By the time the residence and the day care program opened, some of the registrants had changed.

The original intent was to centralize all care of the Greenbriar residents at Park Ridge, including medical coverage, dental care, and other consultation services. This plan was not a viable one, however, as medical coverage could not be obtained at Park Ridge. Thus, the registrants continued to receive primary medical care and consultation services from the health center.

Transportation was another concern. Initially, Park Ridge was planning to purchase a bus for transportation. However, it was decided that a community medical carrier would provide transportation to and from the program for all registrants who requested it.

Lessons Learned

Cross-training staff is crucial.

When hired, the adult day care staff had only long-term care experience. They were somewhat apprehensive about taking on the treatment of a new population as none had a background in working with people who had a developmental disability.

On the other side, staff from the state developmental center had limited experience in

working with elderly persons. In one example, developmental center staff encountered an elderly woman with a developmental disability who had a problem with incontinence. The behavior management technique used for this problem was toileting the individual every 15 minutes. The day care staff believed that she might have a urinary tract infection. Their solution was to increase her fluid intake and send a urine specimen for testing. Further investigation of the problem led to the discovery that her incontinence problem was caused by the change in coffee from decaffeinated to caffeinated. When the coffee was changed back again, the urinary problem disappeared.

We have learned to look at all sides of the situation and to include environmental factors. A useful solution has been to have the clinical staff provide cross-training to staff at both agencies who are directly involved with the registrants.

Sometimes there are inconsistencies among the various regulatory and reimbursement systems in a state.

There was a sizable language gap between the health and developmental disabilities systems which made case reviews and team meetings long and cumbersome. There was also some territoriality regarding who was responsible for assessing and treating registrants in different areas (i.e., nursing, physical therapy, and occupational therapy). The regulations differed between the state's developmental disabilities and health agencies. Medicaid will reimburse the state-operated community residence for the services it provides but will not do the same for an intermediate care facility.

The solution to the problem was getting to know and trust each other, and providing each other with copies of commonly used regulations and definitions. This process helped us to reach common ground. We also schedule our case reviews at the same time, with each team completing its own paperwork to meet its regulations. We are also pursuing the Medicaid reimbursement issue at the state level.



The lesson learned from this problem was that time was our greatest ally because it helped us to know and trust each other. Language and regulations may be stated differently, but knowing that all of us strive for the same goals has helped. We still stumble at times, but we stumble together. We have also made some wonderful new friends.

Having people who live together attend the same day program may not always be for the best.

One problem we noted was that the 10 people, who lived in the same residence and attended the same program five days per week, created tension and behavior management problems for the staff at both agencies. Further, as the program grew to capacity, the registrants with developmental disabilities got less personal attention from the staff, which in turn resulted in behavior problems. The problems led to the discharge of two Greenbriar registrants when their behavior at the program became unmanageable.

Integration can work, but sometimes it does not work well for some persons.

We noted that some of the seniors continued to require a more structured environment and a higher staff-to-registrant ratio than we could offer in adult day care. The discharge of a registrant from the program does not mean that the program or the registrant failed: it may mean that the match between the person and the program was not the best. It may also mean that other, unanticipated, factors may be involved (such as, people who live together should not necessarily attend the same day program -- if they do, time must be planned for solitude and separation).

Take into account the nature of the activities offered within the program and try to adapt them to all the participants.

Programming activities can pose a challenge. For us, it proved to be a difficult one as those activities, which at times satisfied the registrants with developmental disabilities,

were seen as boring or "too low level" for the population which did not have developmental disabilities. Those activities which suited individuals who did not have a developmental disability, were often "over the heads" of the registrants with developmental disabilities and the registrants with Alzheimer's disease did not always respond to either group of activities.

We found that the solution to this problem was to reduce the number of large group activities offered in the program. For small group activities, individuals are grouped according to their level of functioning and interest, or more individualized activities are developed to address specific registrant needs.

Parting Comments

Integration does not always mean assimilation. It is not helpful to try to fit everyone into the same program. We still share common activities, such as participating in music and bingo, but otherwise the activities care plan is as individualized as the nursing care plan. Recognizing peoples' differences in ability and interest is vital to providing a successful program. Also, when starting a program for people with developmental disabilities, staffing should be set according to the number of registrants with the staff increased as the census increases. The registrants and staff will have an easier time adjusting.

Our preconceived notions about each other's systems and people proved to be inaccurate. The registrants have much more in common than not and the same can be said of the staff, and even for the bureaucracies which govern us. Some very special relationships have developed between the registrants and staff of both agencies. Day at the Park has demonstrated that some older persons with developmental disabilities can be integrated within the greater population of medical model adult day care setting users.



A review of the case studies provided us with insights into the state of the art of senior services for persons with developmental disabilities. These insights encompassed both "how-to's" and "lessons learned." It also provided us with a look into a number of diverse and innovative experiences.

The notion of community integration is not new, having been applied to social policy, agency practices, research and personal needs for many years. Integration in older age has witnessed providers and consumers seeking out retirement activity options within the broader community and, more narrowly, within the aging network. There is nothing magical about looking to the aging network for such options. Indeed, with time and perseverance, anyone can find things to do in his or her community (whether the activity is accommodating seniors or persons of all ages).

In the United States, community aging network programs offer a variety of options supported by public funds. In many communities, congregate meal sites, senior clubs, and retiree activity centers have been around for some time. In 1965, Congress made a commitment to the elderly population of the United States by providing for social settings that could serve as gathering places for persons with limited options or of limited means. These modest social settings, over the years, have expanded to the varied types of multipurpose senior centers found in many of our communities today. Some evolved from pre-existing senior centers, others were specifically developed to serve a particular neighborhood or community. These types of settings exist in other countries as well, where such senior or pensioner clubs, neighborhood social centers, autumn clubs, and lunckeon clubs are often underwritten by public funds or supported by membership fees.

Why focus on these? Community integration means being part of one's community, having the same opportunities to use public amenities as one's peers and using these opportunities to live an ordinary life. Further, inclusion means being involved with and an intimate part of the scene of any community and party to the same experiences as other persons of one's age. Being accepted, befriended, and free to pick and choose from what's available are all part of being included -- as are the risks of failure, rejection, and frustration. Senior services within the United States can provide a rich and varied choice of environments for meeting others of your own age, developing new friendships, and being able to recreate, socialize, and learn new things. Thus, these types of settings are ripe opportunities for integration, inclusion, and enrichment.

Qualitatively, senior service settings will vary as much as the people that administer and populate them. Some are housed in spacious buildings, rich in variety and opportunuies, and open to a spectrum of the community. Others, more humble, may offer the barest

Section 9: Commentary

essentials and opportunities -- often only a place to meet and share a cup of morning coffee or afternoon tea. The pros and cons of using such settings are addressed in our companion publication, Building the Future: Planning and Community Development in Aging and Developmental Disabilities. Nonetheless, such settings provide a host of experiences that can illustrate different integration efforts.

When we first clustered these 38 case studies we used a simple approach, drawing upon three prevalent models -- interagency efforts, senior centers, and social and health adult day services. However, as we analyzed the different approaches inherent in these 38 case studies, we realized that we were dealing with familiar models with clear delineations in some cases, mixed models with subtle differences in others, and clearly new and different approaches in others. Thus, we felt that more categories of experiences were needed to fully explore the types of activities and opportunities that were being undertaken or offered.

In the end, we chose these eight clusters for the case studies. There is often overlap among them; rarely does only one method or type predominant. However, each case study was included under the cluster that either most represented the approach used or, in the case of mixed approaches, was most illustrative of a particular effort. These eight clusters (bridging networks, top down efforts, retirement assistance ventures, pull-out programs, senior companion ventures, senior center ventures, social model site programs, and adult day health model programs) represent the types of approaches that are being undertaken to serve and offer integrated services to older persons with developmental disabilities throughout our country (and those being undertaken in other countries as well). Some focus heavily on integrative approaches and some go a step further and press for inclusion. Others represent efforts to provide a specialized day service for seniors that has attempted to use some features of integration. Although, these represent a broad range of approaches, we are convinced that with time more models and techniques will evolve.

What did we glean from these integration and inclusion experiences? We found the following outcomes:

- There are creative and innovative methods being tried to affect community integration and inclusion of older persons with developmental disabilities.
- The variability of approaches reflects a genuine commitment on the part of agencies and individuals to do their best and the "right thing."
- The lessons learned will improve our ability to promote community integration, and with time many of the barriers encountered will no longer exist.

Some Thoughts About Each of the Clusters

Each of the experiences reported within a cluster offer both common and unusual insights into the "how-to's" and "lessons learned" experienced by the project managers as they went about their efforts. We have tried to glean from these insights some of the commonalities and practical approaches for each type of case study included within the clusters. What we learned follows.

■ Bridging Networks

Bridging networks involves linking the developmental disabilities system providers with aging network providers. Such bridging has been done for several reasons. One is that there is a need for coordination of referrals, services (such as transportation), access, site sharing, and dealing with the whole range of day-to-day problems that older persons experience. Another is that there is a need to ensure



that monies used to underwrite the programs for older persons with developmental disabilities flow quickly and properly to the providers within the aging network. Still another is to affect greater acceptance of seniors with disabilities among the public and age peers and to encourage fuller inclusion of seniors with a disability within mainstream aging network programs.

The process of bridging networks can take many forms. Key features of such efforts are that the participants agree to cooperate, agree to achieve common ends, and agree to shape public policies that support bridging. Such efforts, however, are also not without their difficulties. Bridging efforts, as we have found, can be affected adversely by several factors, including changes in key personnel, money problems, shifts in priorities of the participating agencies, and frustrations over lack of agreement of group objectives or time-frames.

In the instances we observed, bridging efforts began small and worked up to have a major impact in their communities. Such efforts usually were undertaken in three phases. The first, we call *explorative*, involved the bringing together of the people who would make up the network. This initial phase led to the group deciding some set course of action. This phase also led to commitments on the part of the actors to pursue the course of action.

The second phase, we call formative, involved acting on a common purpose -- it may be evolving an area interagency agreement, opening up special efforts, developing or funding programs, or undertaking a public or professional education campaign. The third phase, we call consolidative, involved the group adopting an organized structure, becoming a stable and influential force within its community, and affecting public policy.

We observed that network bridging endea-

vors often start as modest ventures, such as bringing together strangers who over time form a collegial bond that strives for the community good. Many of these efforts lead to or are associated with results that produced interagency agreements or other forms of formal social bonding. Many also need outside stimuli to begin their formative activities; others do not and evolve naturally.

What were some of the factors that emerged as important characteristics of effective bridging efforts? We found

- strong leadership involving one or more persons,
- support of state and/or local authorities,
- clearly defined goals,
- successfully executed group activities,
- cross-training conducted within the group, and
- funding or logistical supports provided by a sponsor or underwriter.

We also noted some common barriers, including aging network reluctance to designate an additional target population (in this case, older persons with lifelong disabilities) and concern over sharing already scarce Older Americans Act resources; stamina and commitment on the part of network group members to sustain a long-term effort that involves frequent meetings and pursuit of a defined advocacy or public policy agenda; and loss of key persons who serve as "sparks" for such efforts.

What were the key lessons learned? Interagency efforts can be productive and provide bridges to the aging and disabilities systems. Sometimes they need formal mechanisms to succeed, other times the social bonding that occurs has greater value than formal structures. In all instances, the successful efforts become partnerships with each network/system equally involved and benefitting.



■ Top Down Efforts

Top down efforts are projects stimulated by state agencies and carried out by localities. Such efforts involve state monies or other incentives and changes in policy to support the initiatives. In some instances, these efforts start with state level planning and allocation of development funds. They usually result from recognition that some problem or void exists and that there is a need to address it. Many such efforts start as pilot projects or demonstrations, where the state agency seeks to test out some idea. In others, they may result from a policy shift and a resolve to implement a new program idea. In still others, it may be a means to deal with changes in population needs. Many are done through a local agency which is asked to test out a project idea.

We observed that top down efforts involved a local agency or agencies that actually carried out the initiative; however, the impetus for the initiative came top down from the state. In these instances, several different methods were used to implement public policies, including direct state-operated program development, a competitive RFP (request for proposals) method to select the participating agencies, and providing support monies to the local agency to either test out an idea or get a project started. Often operational monies followed so agencies could continue the program.

In two of the examples we used, the projects evolved through direct state operations at the local level. In each instance, state resources were shifted to favor the project. The state agencies use the projects as tests of further commitments of state policy. Both fiscal and personnel resources were allocated and state officials backed up the efforts with public appearances and interagency arrangements. These efforts were the pilots upon which further program development rested. In another instance, the state tried to promote program development of one type, but found that an innovative agency was developing another

program model. This model, in turn, was allowed to flourish and became the basis for further program development — in essence replacing the original.

In another example, the state encouraged a program to develop new services to show that it could be done even under the most adverse conditions. In still another effort, a state agency encouraged a new program model and funding stream to evolve through a competitive application process. This gave creative and innovative agencies "free rein" to develop a series of programs that eventually took hold all over the state.

What was common in all these efforts? First, each began with the state agency offering funds to begin a new program. Second, the agency received support from the state and used the demonstration process to help the state adjust its policies and/or regulations to adapt to a new program model. Third, in most of these situations, one individual was instrumental in beginning the change in state policies and in stimulating new program development.

What were some of the factors that emerged as important characteristics of effective top down efforts? We found

- recognition of need for change in public policy,
- available fiscal and personnel resources,
- comprehensive community education,
- lack (or waiver) of restrictions or regulations,
- support of the use of volunteers, and
- commitment to working out problems.

We also observed some common barriers, including freeing up funds and other resources in the first instance; trying a top down effort without concomitant network building efforts; and not willing to "take the heat" in making systemic or regulatory changes that impede development.



What were the key lessons learned? One lesson is that the state has the capacity and resources to stimulate program development and aid in accessing existing services. "Money talks;" that is, grants and other allocations of resources go far to make projects like these work. Another lesson is that problems, however seemingly insurmountable, can be overcome with creative management and good, reliable people. As with other examples throughout the casebook, the participation of a key person, a "spark," helped to make such projects work. In addition, state efforts must allow for flexibility so that innovation can emerge. Lastly, often the state, if it stimulates such efforts, can bring a degree of leverage that frequently is unavailable in other situations. State level agreements or interagency activities can force or effect cooperation at the local level among agencies that report or are accountable to state agencies.

■ Retirement Assistance Ventures

Retirement assistance ventures aid someone with the task of retiring. This process includes preparing mentally for a change in life activities, getting to know new places and people, and gaining the expertise to manage one's time and resources to enjoy retirement. Most approaches to retirement occur naturally and are part of one's life tasks. With persons who have had sheltered lives and limited experiences, retirement often needs to be facilitated, guided, and nurtured.

Many models exist that draw upon mentoring or aiding older people with retiring successfully. Among the facilitated retirement examples we observed, many drew from a variety of experiences; some loose, some more structured. They all, however, had one thing in common -- they aided, by example or by direction, older persons with a developmental disability to use aging network resources within their community.

This process was done in several ways, but the predominant means was by pairing an older person with a guide or a "coach" or by specifically building retirement time-use skills by teaching or exposing the senior to guided retirement experiences. Such facilitation models have produced many sound lessons, including: retirement (like all life tasks) requires a period of preparation and emotional adjustment; the abilities to do things associated with retirement can be taught by modelling; you can never anticipate all the things that may impede your efforts to aid a person in adapting to retirement; retirement often works best when experiences draw from a potpourri of situations; each older person will adapt at his/her own pace (do not expect that everyone will adapt equally well); and preparing aging network personnel for older persons with lifelong disabilities will help the access and adaptation process.

Barriers observed included the lack of sensitivity among staff involved in other aspects of the senior's life (causing scheduling conflicts) and lack of cooperation around retirement training, the lack of funding to pay for people who aid with retirement training, finding the right persons to serve as retirement coaches, and unfavorable attitudes and lack acceptance on the part of other seniors. Other barriers encountered included the lack of communication among agencies serving the individual, getting referrals from the developmental disabilities agencies, fear of change among the seniors with developmental disabilities, and over-optimism by staff as to the capability of some seniors to be on their own.

What were some of the factors that emerged as important characteristics of effective retirement assistance ventures? We found the following to be of primary importance:

- · focus on options and choices,
- special focus on training social skills,
- vie of retirement assistants or coaches.
- comprehensive community education,



- practices that can surmount anticipated and unanticipated barriers,
- careful choice of assistants or coaches,
- · design flexibility and creativity, and
- cooperation between the developmental disabilities and aging networks.

What were the key lessons learned? Helping someone to adapt to new situations can work better than expecting that person naturally to know how to use that situation. Planning means of social bonding and orientation to one's community can aid in successful aging. Role models can be friends, volunteers, or even paid companions. All have a valuable contribution to teaching retirement skills. Such efforts need not be large productions; many can be operated on limited resources.

■ Pull-Out Programs

Pull-out programs are efforts where two or more groups of people are drawn together for a common purpose during a specific period. In many instances, the host program may operate a specific site, such as a senior center, or a disability agency retirement program. The operators of each program will schedule common activities that help the interaction of members of each program with those of the other. Sometimes these programs are designed around a one-time activity such as a visit or trip; other times they are designed around an on-going activity such as maintaining a garden or a travelling chorus.

We found that agencies set up such programs under a variety of conditions. These conditions included: not having all the resources to arrange for complete use of another's program, trying to overcome attitudinal barriers among the mainstream senior program participants, using these opportunities to try new ideas in sharing activities, and trying "reverse integration." These types of programs usually had an individual who was personally committed to seeing them work and

who wanted to break down attitudinal barriers among the seniors. The program managers worked to get seniors to accept the invitations and come to participate in the common activity. Oftentimes, special incentives were used, such as providing transportation, paying for the activity, or celebrating some special event (a birthday or some theme or event of particular interest to all of the seniors). Some of the program managers found that the distinctions among the seniors began to disappear once the seniors got captivated by the activity.

The most difficult barrier to overcome was often not the attitude of seniors, but simple logistics such as having enough vans, funds to pay admissions, or enough staff to accompany all the participants. These seemingly mundane matters were often of the utmost concern in making each outing a success.

We found some interesting benefits for such programs: they bind people of different back-grounds or affiliations during a period when each person can get to know the other better. The goal in each case is to "break down the barriers" and let natural social relations and even friendships evolve. Sometimes, these efforts were successful. At other times, they offered a period of common camaraderie which was then followed by each participant going back to his/her own site. Did they have a positive effect upon their participants? The program operators thought so.

In our examples, we noted the breaking down of psychological and social barriers, so that the participants got to know one another better. We also observed that such joint activities broke down stereotypes and misconceptions (which helped mitigate these when they were shared with the other participants at their home site). These models are not unique; that they are being tried in greater frequency speaks well to the creativity of people working with seniors and working toward breaking down artificial social barriers.

What were some of the factors that emerged as important characteristics of effective pull-out programs? We found

- · activity chosen of interest to everyone,
- use of small groups for common activities,
- care and attention paid to interpersonal relations among participants,
- activity supports/logistics thought out ahead of time,
- ability to draw upon extra resources of host agency (vans, staff, supplies)
- · physically accessible activity sites, and
- support of administrations of agencies participating.

What were the key lessons learned? Creativity and innovation often must struggle with lack of financing and administrative problems. Such programs can only work when an individual "spark" sets the tone and oversees its workings. They are excellent "ice breakers" in getting the community to think of inclusion and common use, and they are an excellent means of fostering friendships and greater public awareness of people growing older with disabilities. Most were undertaken as projects within a large agency which could help when funds or other supports went awry.

■ Senior Companion Programs

Several situations relied upon the model of the senior friend or companion to help someone with a lifelong reliance upon the disability system to begin to navigate the unchartered waters of the aging network. Such companion models worked because they offered both role models for later age and a friend to help broker unexperienced situations. These models ranged from programs where a retirement coach was used to help guide the transition to senior services to situations where seniors were paired because they wanted to mentor and then share some collective experiences. We also saw the creative use of the federal ACTION

agency's Senior Companion Program, where senior volunteers helped in situations that promoted greater use and enjoyment of available senior activity programs.

What was common in all these efforts? They were usually small ventures operated under a strong staff person committed to seeing the process work, the head of the project spent time visiting the senior center and activity sites and getting to know the administrators and the site ambience. Also, the use of the community's media to spread the word about the venture and to recruit volunteers, and being flexible and responding to the desires of the seniors to learn about activities they liked were very important.

The most difficult barriers to overcome were the time and patience it took to nurture and coordinate a system of volunteers, getting appropriate and adequate referrals for such efforts, and making suitable matches between the volunteer companions and the seniors wanting to retire. Additional barriers were encountered when the seniors did not have enough funds to participate in an activity, when they wanted to use programs in a building that was not physically accessible, or when their social skills were not on a par with other program participants.

What were some of the factors that emerged as important characteristics of effective senior companion programs? We found

- · involvement of a key person as overseer,
- use of volunteers or part-time staff,
- accessible neighborhood senior center program or activity resources,
- special attention to training and supervision of volunteers/part-time staff, and
- individualized and mainstreaming approaches.

What were the key lessons learned? The foremost was that one cannot assume that an older person will automatically make use of



their retirement time and that programs used to help explore the use of available options proved helpful. Volunteer-based programs are not easy to operate and involve a great deal of pre-planning and support. Senior companion programs are often more normative because they provide an age-peer, work on a one-on-one basis, and provide a more meaningful basis for assimilation. And, most importantly, these programs use the natural resources of the person's neighborhood or community and offer an opportunity to that person to become more adept at making the best of the choices and options available to him or her.

■ Senior Center Ventures

Senior center ventures aid an older person with a developmental disability to use a neighborhood or community senior center. The most common community resource available under Older Americans Act programs is the community senior center. Attendance and use of senior centers varies around the country; overall about 10% of persons over the age of 60 are frequent users of such programs. Senior centers are sites, often in neighborhooduse buildings such as surplused schools, church social halls or rooms, apartment buildings or senior housing units, neighborhood social centers, or even store fronts, that provide a social setting that enable seniors to congregate, relax and socialize, and participate in various activities. Some are community social service centers with a racially and culturally diverse membership, others are more like "clubs" with a less dissimilar membership. Many senior centers are also congregate meal sites; some are multipurpose and provide avocational activity, workshop, and physical exercise/fitness facilities. Some are simply a place to come and talk with friends, share a beverage, watch television or read a newspaper.

This type of integration activity generated the greatest number of examples. We found this to be true because many centers have already undertaken efforts to reach out to seniors with disabilities, while others have become the target of agency activities to promote integration. The case studies we chose for inclusion in the *Casebook* are illustrative of the variety of activities that have been undertaken to aid older persons with developmental disabilities to use the facilities at their local senior centers. These are the most prevalent community integration efforts undertaken and as such offer the broadest variety of experiences.

The approaches used to help seniors with a developmental disability use their community senior center varied considerably. Some worked to help the senior center become a more receptive environment. Others took steps to aid seniors with a developmental disability (singularly or collectively) become more familiar with one or more senior centers and become more at ease with using the centers. Still others found that the only way they could get their "foot in the door" was to set up an enclave program. Some undertook their efforts with project staff, others did staff sharing arrangements, and still others used a senior friend or companion approach. Some tried formal arrangements, others went ahead on their own. Still others used a matchmaker or broker approach that paired seniors with the center most suitable to their interests and nceds.

The data we worked with were insufficiently detailed to assess what variable contributed to the use of enclave models versus individual assistance models. Although we suspect that there is no easy means to identify this variable, we can offer some speculative thoughts. Perhaps, it was a combination of the level of social sophistication of the seniors with a developmental disability and the ecological nature of the particular senior center that made the difference. Some of the experiences cited showed that mere contact among program administrators was sufficient to effect access and use, others involved a more complex set



bly devalued.

of negotiations with the center's Board and the members themselves. We wonder, although the end was the same, whether opening the decision making process to that level is warranted and perhaps inconsistent with various federal statutes (including the Older Americans Act and the Americans with Disabilities Act) that specifically authorize equal access. We were also not surprised that in some centers the agencies ran into significant opposition

from the membership. Group dynamics being

system is not easily made by a group seeking entry when it is marked as different or possi-

what they are, any new entry into a tight social

These varied approaches provided us with a richness of experiences from which to draw. We were pleased with the diversity as it proved that no one approach will work to the advantage of all seniors with a developmental disability, nor will it work similarly in each effort undertaken by a single agency. We suspect that irrespective of whatever approach is tried, entering a community senior center will depend heavily upon the orientation of the staff involved, the nature and character of the seniors (both the seniors seeking entry and those who make up the membership), the agency's philosophy, and the resources and supports provided. In our experience, we have observed many successful efforts occur with little or no financial support solely on the tenacity and commitment of one person. In others, we have observed that "money talks," and that a senior center administrator becomes more receptive when cost-sharing or donations of funds or resources are involved.

Of all the approaches we studied, this one has the least amount of common features. Perhaps, this is because of the heterogenous nature of senior centers and agency agenda. However, the common features that can be teased out include: an emphasis on preparing seniors who will be integrated on how to behave, smoothing the way by getting agreement from the senior center management, guiding

involvement in senior center activities that are of interest to the senior with a developmental disability, and using other seniors to help promote the social entry (either companions or key members at the center).

Barriers encountered varied according to the type of venture. For example, with enclave models, staff sharing became a barrier when union or work rules conflicted within the participating agencies. Having a specific space for the enclave program was both an asset and a barrier as it provided dedicated program space, but also tended to differentiate the participants. Irrespective of model, acceptance was affected by the behavior of the seniors with a developmental disability. As in any social setting, the seniors had to learn the "hidden rules" that governed interactions and other behavior in the centers. Thus, another barrier would be the lack of preparedness to act appropriately in the social situations presented by the senior center.

With individual integration models, smallness sometimes became a barrier. In rural areas or small communities, one or two seniors can blend in, but three or more may stand out. This same number would not be significant in an urban senior center with hundreds of users. Additionally, prejudice on the part of a center director can block the use of the agency for any number of seniors, as can injudicious use or incidents -- as when a van load of seniors appears without preparation and causes disruption with lasting adverse results.

What were some of the factors that emerged as important characteristics of effective senior center ventures? We found

- strong interest in use of senior center as integration site,
- involvement of a key person as "spark" to get effort going,
- low cost efforts,
- special focus on training social skills and on social rules of center,



- · receptivity by the aging network,
- integration of individuals or small group,
- autonomy and self-sufficiency promoted among participants,
- targeted involvement of other seniors, and
- participation in center activities.

What were the key lessons learned? Many of the efforts to use senior centers can be done at little or no cost. Such efforts go much further if you don't run into resistance on the part of the site managers or other seniors routinely using the site. Although the force of law is behind your efforts, you do not score points by forcing people to accept one another. Volunteers, particularly other seniors, functioning as senior friends can be a valuable resource. Aiding individuals to be integrated into senior centers can be more effective than trying group integration. On the other hand, if nothing else will work then aiding a group to become site users is a workable device.

■ Social Model Site Programs

Social model site programs provide a day service composed of activities and supervision for seniors with special needs. Adult day services -- commonly termed social model day care -- provide a range of supportive services to needy people who are elderly or chronically impaired. Generally the focus is on aiding the family who is providing care for the person evening, overnight and weekends. These programs provide respite for family members who may work or have other family responsibilities. However, such programs have recently become more of a focal point for supportive services also directed toward the individual placed within them. In many localities, such programs are similar to day activity programs provided to younger age persons with developmental disabilities who do not qualify for a work-oriented program or whose complexity or severity of disability is such that they require a period of habilitative care before moving on to another type of program.

Such programs often offer a range of activities that for seniors with a developmental disability equate with varied retirement activities, particularly for those seniors who need a more structured site than that of a senior center or who may have retired from elementary workshop activities. Many of the examples of senior programs we received fell into this category of services.

The types of activities that are offered and how the programs are operated vary broadly. We found a variety of approaches ranging from those that were set up to be the senior adult day care resource for their community -- and thus open to all seniors irrespective of type of impairment, to those that were set up as community retirement activity programs for the seniors with a developmental disability. Some are run like senior centers with a potpourri of activities made available. Others tend to take the day habilitation model and extend it to seniors, changing the nature of activities to accommodate different lifetasks. We also found that program auspice varied. Some social model site programs are operated by aging network agencies and thus are open to a variety of older persons. Others are operated by developmental disabilities agencies and predominantly serve seniors with developmental disabilities (although not in all cases).

The common features? They relied on a greater staff-senior ratio; had admission and discharge policies; often had individual program plans; were more stable for day-to-day users; built their budgets around a "caseload;" and served a more physically or cognitively impaired clientele. These programs were less costly compared to programs for younger age individuals who are chronically impaired. Much of what went on in the programs was a function of the agencies' philosophy, agenda and commitment of resources.

The most difficult barriers to overcome included reconciling the differences in approaches and perceptions to programming between the developmental disabilities staff and staff of a social model site program, reticence on the part of developmental disabilities providers to offer



referrals and coordinate activities, resistance on the part of some parents or other family members to view the program as offering something worthwhile to a senior with a developmental disability, and when such programs are run by a developmental disabilities agency, resistance on the part of aging network agencies to have the seniors involved in some of their activities.

What were some of the factors that emerged as important characteristics of effective social model site programs? We found

- variability in design, including senior center, retirement program, activity center models.
- special focus on individual needs and interests.
- · low cost efforts.
- · variable and flexible program content,
- · mixture of different kinds of persons,
- · involvement in community activities, and
- cooperation between developmental disabilities and aging networks.

What were the key lessons learned? One major finding was that programs such as these can be run at a relatively low cost. Another finding was that the approaches taken within the programs can be varied and flexible depending upon the types of seniors being served. Such programs, when operated by a disability agency, can also become a resource for the greater community, particularly among elderly individuals living at home and who have age-associated impairments.

■ Adult Day Health Model Programs

Adult day health model programs are situations that provide a day service composed of activities and supervision for seniors with special needs under the direction of a physician. The program is a variant on the adult day service model. These programs are similar to the social model programs with the exception that most funding comes from Medicaid, third party payor or fees, and admission is by a physician's prescription. Because of this factor, services are

more medically oriented, including health monitoring, medication administration and review, specialized therapies, and nursing care. Activities are often similar to those in social model programs. Because of the specialized nature of these programs extramural activities are generally not offered and integration is more a function of case mix.

These programs exist in many communities, although in not as great a number as the social model programs. Because of the nature of the services, many may serve seniors with more severe levels of impairment or disability. Many also admit younger age persons with chronic physical or mental conditions as well as developmental disabilities.

The common features of adult day health model programs are similar to those of the social model site programs, with several exceptions. Many admit seniors who are more physically or cognitively impaired and provide more of a focus on health related services. These programs are rarely operated by developmental disabilities provider agencies, most are operated by health or other providers — depending upon the licensing laws of the state. In contrast to social model site programs, these programs are licensed and because of their health related admission and service policies and requirements get a higher rate of reimbursement.

The most difficult barriers to overcome included: dealing with inconsistencies between the regulations or requirements of the health system that licenses the program and the developmental disabilities system that is making referrals; having staff that are inexperienced with working with seniors with lifelong disabilities; getting referrals from mainstream developmental disabilities sources; and working out the differences in techniques and philosophies between the developmental disabilities and health care systems.

What were some of the factors that emerged as characteristics of adult day health model programs? We found

participants mostly persons other than



- those with developmental disabilities,
- formal payment systems and higher costs,
- · stress on health related care and therapies,
- · intramural program focus,
- program content dependent upon state regulations,
- · integration a function of case mix, and
- participants generally may be more impaired, frail, or elderly.

What were the key lessons learned? Health providers, as they move to serve persons with developmental disabilities, find that they are entering a system with differing requirements. Program activities need to be designed to accommodate a variety of impairment levels and interests. Such program efforts are doable, but be careful to expose staff, used to working solely with persons whose primary need is health care, to habilitative technologies and knowledge about developmental disabilities.

As more adult day health program providers become aware of elderly persons with lifelong disabilities within their community, more will be seeking to admit them into their programs. Care must be taken that the medical/health orientation of these programs takes into account the needs of persons with developmental disabilities and that special consideration be given to training staff and administrators in developmental disabilities. Although these program may at times be most costly than other types of formal day programs, they provide an opportunity for elderly persons with significant functional impairments to receive a range of services and activities in a comfortable day program environment under the supervision of medical or health personnel.

Parting Comments

What did we glean from the case studies and the experiences of our community integration project? We would see this advice falling within three broad categories: how we use language, what are our values toward aging, and what is the political/policy climate of the community. We feel that all these can substantially affect integra-

tion efforts. A few comments about each of these.

How we use language.

There is a difference between the terms "aging" and "growing older." There is also a difference between the terms "geriatrics" and "gerontology." Aging is the physical process of bodily and functional changes associated with progression through the lifespan. Growing older involves the psychological and social perceptions of ourselves, by ourselves and by others, as we age. Geriatrics is that branch of medicine dealing with the maladies of old age. Gerontology is that branch of study that examines old age and its physical/social/psychological processes.

As workers enter the world of working with older people they are often unsure of the language and concepts associated with it. In addition, many see old age ripe with infirmities and as a negative process, rather than another stage in the lifespan that often is associated with more free time and constructive involvement in recreational, social and personally rewarding activities and a time for redefinition of one's life-goals. Thus, many workers remain fixed with concepts that, rather than evoking wellness and acceptance, promote ill health and segregation.

We know well that words evoke varied images and meanings, and, as effective marketers have long ago learned, to sell a product you must paint an enticing word picture. Not only is the market affected, but the imagery evoked by the words also restrict or broaden the workers who carry out the day-to-day tasks. For example, when we name a program the Center City Geriatrics Program we conjure up an image much different than when we name it the Center City Senior Center. Main Street Social Center, or the St. Adelbert's Retirement Society. We do the same when we call the people using the program, "clients," "patients," "geriatrics," or any other form of clinical labelling. We can certainly just as adequately use terms like "people," "seniors," "members," and the like. If it is not our intent to have the public (or the staff, or the users) perceive the seniors in a program as infirm, fragile, or incom-



petent, then why use terms that conjure up such images?

Another is how we characterize people. Clinical histories and records, important in school, training, or clinical settings, are not important in social settings. When making a referral to a program or making an introduction, is it important to know a person's IQ, clinical history, diagnosis, or disabilities? The labeling process that we often engage in for younger age people is unnecessary in social settings for older people.

Some situations may call for some impairment information. Perhaps, if a communication disability will impair getting along, telling someone that "Ms. Smith has a hearing impairment" may be beneficial, but only if it is also done for other users or members of a senior center or program. This is not to say that knowing something about social or functional skills is unimportant. But, saying

"Ms. Smith is interested in coming a few days a week -- she is interested in the crafts program and in making new friends"

is a much more powerful image than

"Mary Smith, who has been in our retardation center for the past 20 years, is only mildly retarded, and needs a place to come once or twice week."

All people have foibles. Don't focus on them, let the people sell themselves.

Such factors also affect how staff perform and how creative they are in attempting new things. The prevailing language in a program can either restrict or open up the program. If the users are referred to in clinical terms ("clients," "patients," "geriatrics") then staff think in a way that promotes age-related pathology and look for limitations. If the language promotes dignity and the self-worth of the users, then staff will think in terms of their assets and operate with a "can do" attitude.

How we use the program philosophy and orientation.

The program philosophy comes from the basic belief system related to our personal values and how we value the people with whom we work. Ask yourself, "What do you believe?" This includes your own personal values toward individuals with a disability and your own feelings about aging and old age.

- ✓ Are you comfortable with people with disabilities being involved in the life of your community?
- ✓ What type of words do you use to describe aging? How does it make you feel?
- What are your natural reactions when you are around older people or people with disabilities in the community?

This may seem like a fundamental issue, but it is surprising how many individuals work as staff in programs serving people with disabilities who may not have a commitment to community integration and full inclusion.

Look around and get a sense of the prevailing values within your agency. Do the values promote integration, age-appropriate language, dignity and autonomy among your clientele, and most of all, do they promote risk-taking?

- ✓ Is there a stated intent that the seniors in your program or who come for assistance will be integrated first, segregated last?
- ✓ Is there a corporate commitment to enabling you to negotiate and fully use the natural resources and amenities of your community?
- ✓ Is your program isolated or part of the greater community?
- ✓ What are the visible signs of discriminating values within your building -- are there segregated rooms for "staff" and "others?"

Another consideration is the underlying as-



sumptions of what old age means. With younger age persons with developmental disabilities we tend to use the developmental model as the underlying structure. We believe that new learning is a continuous and that we are always striving to promote ever greater independence and self-direction capacities. With old age, some of these underlying beliefs become less relevant. Here we may adopt a different foundation. In gerontology there area several concepts that can help guide us.

- ✓ One is the notion of successful aging. This is the capability of an older person to retain his or her ability to function as independently as possible in old age, by not needing to be institutionalized, by remaining competent in self-care abilities, by remaining physically capable, by being able to get about by oneself, and by maintaining one's autonomy (see our manual, Building the Future, for more information on this notion). The components of this notion can be built into the strategies that are used to provide a program or retirement experiences.
- Another notion is that of productive aging. This notion centers more on accomplishments in old age, including work, volunteering, and actualizing personal goals and gains. For those seniors whose interests include work or other gainful activities, strategies can be developed that aid them in furthering or achieving these goals. The overriding theme is the promotion of independent, dignified, and productive lives. This notion is also linked to how retirement occurs. In most situations, retirement should be self-defined and not rigidly prescribed by chronological age or situation.
- ✓ Another notion, interdependence, is linked to the building of socialization skills and reciprocal reliance upon others. As vacational striving and social competitiveness become less cherished values with the progression of age, as people become more settled and more aware of the value of interdependent friendships, the development of socialization opportunities is an important program feature. The uses of various

features (reminiscence, group discussions, shared activities, and the like) all speak to fostering interdependence.

These are important considerations. Among the program efforts we observed, we noted that those which were the most successful with using inclusionary activities were those that promoted these efforts without restraints. They managed to convey both in language and philosophical commitment a consistency within their activities. The program and activity strategies were age-appropriate, offered challenge and respect, showed an awareness of the developmental tasks of aging, and looked to novel and creative ways of helping people enjoy their lives.

How we use the environment.

Environmental issues can take on many features; some include the attitude toward supporting aging program related efforts, others may include what collateral supports, such as training and public education, are available; still others look to how such efforts are seen and evaluated. First, some thoughts on the support features.

What is the environment like in which you are trying to function? One way to eke out what you have to contend with is to ask:

- ✓ What is the political climate in your area?
- Do the state mental retardation and developmental disabilities agency and the state aging agency have a public policy commitment to promoting and supporting community integration?
- ✓ Is there an interagency agreement or have there been common budget allocations?
- ✓ Are you able to secure dedicated funding for senior retirement program efforts or aid in using senior centers and other similar resources?

Included among our case studies are some examples showing how the "sparks" (those key individuals who seem to get things done) went



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out of their way to engage policy makers and nail down financial commitments so that their efforts would succeed. This is not an easy endeavor and takes a great deal of personal initiative and commitment. Integration efforts, we found, only seem to gel when the environment is such that supports can be mustered and used. Certainly, not all efforts need a formal structure; there are many success stories where someone worked with virtually nothing and built an enviable program or

However, we have found that strategic efforts need forethought and planning. Although financial commitments may not always be forthcoming, policy and administrative commitments can usually be obtained. A corollary to this is the types of supports you can call upon to aid you in preparing both the community and your staff. Asking "Are there training and education resources available that I can tap?" can often help produce unexpected allies. Many universities and provider agencies have developed or provide training programs that focus on aging and developmental disabilities. Such a resource may be available in your area or, if not, there may be support for offering training in aging, senior services, integration practices, and the like to help more fully develop your staff from other places. In our companion handbook, Building the Future, we discuss many of the resources that can be tapped to provide for education and training, as well as expand upon what could be included as content or approaches.

A second concern asks: what are basic criteria for evaluating efforts directed at community integration? This is a complex subject and we can only offer a quick observation. With the first two types of efforts noted in the Casebook, bridging and system change efforts, the key appears to be the nature of the relationship between the developmental disabilities and aging networks and the freedom given to providers to try new ideas.

With the next four, retirement assistance, pullout, senior companion and senior center efforts, there is a variety of approaches that can be used. However, we would propose that a possible key appears to be the degree of inclusion promoted and the care given to preparing the individual to

assimilate with his or her peers or use community amenities. With regard to the last two, social and adult day health model programs, these represent more traditional models where people with impairments are served. With regard to assessing integration, the key may not be case mix, as the functional abilities or liabilities of the participants may be similar. From our observations, the key features appear to be the *nature* of the intramural activities and the extent of extramural activities.

Lastly...

What does the future have in store? The latter 1990s will be an era of greater public acceptance of disabilities once public amenities conform with the provisions of the Americans with Disabilities Act. The 1990s, too, will be an era of policy maker recognition of the enormity of the coming senior boom where one out of every five Americans will be an elderly person. These two phenomena will harmonize to make the environment that much more receptive for integration and inclusion efforts for seniors with lifelong disabilities.

Unfortunately, the latter 1990s will also be a time of budget difficulties and a restructuring of values that will take this nation into the next century. These conflicting, sometimes complementary, forces will have to address the complexities of a nation with a growing older population, a pending "senior boom," and a greater awareness of the inclusion of people with disabilities.

These 38 case studies are but examples of the many efforts across the nation that are being undertaken to make old age a finer time for seniors with developmental disabilities and promote the living of ordinary lives. Whether this comes to be will be due largely to advocacy and support of the aging network. It will also be due to learning from the experiences of others. As one of our contributors noted, "I'd do things differently next time based upon what I learned from my experiences." It is our hope that these integration experiences and our own parting comments will prove helpful in shortening the learning curve for the efforts yet to come.



Community Integration Project in Aging and Developmental Disabilities New York State Office of Mental Retardation and Development 144 Holland Avenue, Albany, NY 12229